Child and Youth Mortality Review Committee

Te Rōpū Arotake Auau Mate o te Hunga Tamariki, Taiohi

Fifth Report to the Minister of Health Reporting mortality 2002–2008

Disclaimer

The Child and Youth Mortality Review Committee prepared this report.

This report does not necessarily represent the views or policy decisions of the Ministry of Health.

Chair's Introduction

Chairing this Committee has been both a privilege and a torment.

The privilege arises from the rights given to the Mortality Review Committees that allow the linking of data from many sources to achieve an understanding of lives and deaths in order to inform efforts to prevent similar deaths in the future. It has also been a privilege to work with so many dedicated people from widely varied walks of life who share the common goal of reducing the toll from the untimely death of infants, children and young people.

Once understanding is gained it becomes tragically clear that many deaths could have been prevented. The torment arises from recognising the level of suffering and grief each death brings for family, whānau and friends, then watching preventable patterns of death being repeated. A major challenge for CYMRC is using the knowledge gained to catalyse changes that will make a difference.

Now with seven years data available for analysis, CYMRC has been able to move to a new phase of development. This year our annual report contains chapters exploring five specific issues in more depth: Sudden Unexpected Death in Infancy, Drowning Under Five Years, The Risk Taking Years – Unintentional Injury in Young People, Suicide, and Systems Issues. These topics were selected as each contributes a substantial proportion of preventable deaths.

For some types of death where good systems for prevention already exist, our main role is providing detailed information to guide the actions of others. In other areas systems are less well developed and there is no "socket" for CYMRC to "plug" in to, to provide information to activate a "machine" that will action and fine tune preventive interventions. Examples of the latter situation would be the prevention of deaths related to risk taking behaviour in young people, prevention of sudden unexpected death in infancy and some types of injury deaths. The Committee has attempted to take a strategic role in sudden unexpected death in infancy prevention by working with providers of services.

The last year has seen a rapid roll out of local child and youth mortality review groups to every district of the country. When each group forms new connections across and within, sectors have developed providing a pathway for information gathering and a system for local influence. These groups work to define the causal pathway[1] that lead to death and then identify points at which this pathway could have been interrupted. Where local action is identified that can prevent similar deaths the members of the group are frequently able to act. Groups also consider and, where possible, work to improve care after death that can minimise suffering and ensure families and friends are aware of available support services.

It is now true to say New Zealand has a child and youth mortality review system that reaches every corner of the country. Considerable work is still required to allow this system to reach its full potential. Unfortunately this work is much needed as New Zealand lies at the top or close to the top of international league tables for too many classes of death.[2]

Nick Baker, Chair

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[1] The Causal Pathway is the chain of events that leads to death including pre-existing contributing vulnerabilities and circumstances, as well as the nature of the fatal events and how they came to interact with lethal consequences.

[2] For example, see OECD 2009a, OECD 2009b, or UNICEF Innocenti Research Centre 2001.

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Executive Summary

The fifth annual report of the Child and Youth Mortality Review Committee (CYMRC) takes a slightly different approach to previous years' reports. Past reports have taken a broad overview of the data; this report looks at specific causes of death, their circumstances and contributing factors. (For comparison with earlier reports, see the appendices, which contain all the tables previously reported in the body of the report. The appendices can be found online at http://www.cymrc.health.govt.nz)

The CYMRC database holds data for the time period 2002–2008. The 2008 data is, at times, incomplete due to cases awaiting coroners' reports. To allow consistency of reporting rate calculations, rates are based on the five year period 2003–07. The 2008 data is included in the appendices and is included in the analysis in some sections of the report.

The CYMRC data shows that there are two periods that are most dangerous for children and youth: the first years of life (0 to 5 years) and the teenage / young adult years (15 to 24 years). (See Figure 5.1.) This report therefore focuses on some of the greatest hazards that are encountered by these age groups.

Chapter 1 considers sudden unexpected death in infancy (SUDI). A national SIDS[3] Prevention Campaign was launched in New Zealand in 1991 and resulted in a large decline in SUDI mortality during the early 1990s. Although rates for European babies declined markedly, declines for Māori babies were much less marked. During 2003 to 2007, 328 New Zealand infants (aged 4 to 52 weeks) died as a result of SUDI. Of these deaths, 202 infants were Māori and 42 were Pacific. The CYMRC is currently working with the Ministry of Health's Child, Youth and Maternity Policy team and service providers to develop SUDI prevention strategies, especially for Māori and Pacific families. These strategies must bridge the gap between what is recommended for SUDI prevention and what actually happens for infants. The Committee believes that a substantial reduction in numbers of SUDI (approximately 60 per year) in New Zealand is achievable and should be a high national priority. Attention to the needs of high risk Māori infants is paramount.

Chapter 2 examines the drowning of young children. During 2003 to 2007, 108 children and adolescents died as a result of drowning. The rate of drowning deaths in New Zealand is high compared to other OECD[4] countries, and the CYMRC has advocated for change in a number of areas to reduce drowning deaths. These include adapting the information in Well Child books about safe bathing, and making submissions to, and being involved in, ongoing discussions about possible amendments to the Fencing of Swimming Pools Act 1987.

Chapter 3 reviews unintentional injury deaths in young adults aged 15 to 24 with a focus on risk taking as a contributory factor. The three major causes of unintentional injury deaths for this age group are motor vehicle, poisoning and drowning, together causing 785 deaths during 2003 to 2007. Simon Denny argues that risky behaviours are part of normal development. Harm reduction must focus on making the environment in which our young people grow to maturity safer and developing risk competence, life skills and resiliency within young people. Development of these skills requires the creation of learning opportunities, stimulating environments and adult support to improve perception and assessment of risks. Approaches to injury control tend to focus on specific policy areas such as road, workplace, water or school rather than taking a developmental viewpoint and

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[3] SIDS stands for "sudden infant death syndrome." SUDI stands for "sudden unexpected death in infancy." SUDI is a broader term than SIDS as it includes both explained and unexplained causes of death. Explanations of abbreviations and selected terms used in the text can be found in the Abbreviations and Glossary at the end of this document.

[4] Organisation for Economic Co-operation and Development.

focus specifically on the needs of young people. Alcohol use is part of many risk taking behaviours and contributes to mortality and morbidity.[5]

Chapter 4 considers death by suicide in those aged from 10 to 24 years. International comparisons show that New Zealand has the highest rates of youth suicide in the OECD.[6] Every year approximately 110 young New Zealanders (aged 10 to 24 years) die by suicide. This accounts for about a fifth of the total number of suicides each year in New Zealand. A clear understanding of the risk and protective factors for suicide prevention that are relevant to New Zealand youth and ongoing information about the rates and causes of suicidal behaviour are necessary to develop effective population-based prevention strategies. The CYMRC data provides statistics on youth suicide from 2003 to 2007, while the findings from the *Youth2000* and *Youth2007* surveys provide a greater understanding of the reasons that might be behind youth suicide in New Zealand.

Chapter 5 examines systems issues that appear across all types of deaths and across all age groups. Although these types of issues are common, policy recommendations are difficult to develop because the layers of contributing factors are often incredibly complex. The CYMRC recognises, however, that systems issues must be tackled, despite the complexity and challenges associated with initiating change. In many cases risks were clustering in or around the individual prior to death but no system recognised the issues. Systems to assess risk and intervene need to keep being improved. Services do not always work together to provide coordinated collaborative care and information sharing and it is too easy for service gaps to form, especially at times of transition. The Local Child and Youth Mortality Review Process has proved to be a good tool to address systems issues at a local level. Fragmentation of information collection and storage results in missed opportunities for prevention at personal and population levels.

Recommendations

Each chapter of this report highlights recommendations that the Committee believes can reduce child and youth mortality and morbidity. They relate to legislation, policy (national and district), practise points and community messages. The committee has followed recommendations from previous reports and a summary of progress can be found online at http://www.cymrc.health.govt.nz, *Fifth Report to the Minister of Health: Reporting mortality 2002–2008,* Appendix L.

With the greater detail available in this report it has been possible to make a large number of recommendations and those working in the relevant areas are encouraged to read the Chapters in detail. It is, however, vital that the most important messages are not lost amongst all the others. The five areas of highest priority for action are:

1.   SUDI prevention (chapters 1 and 5)

The Ministry of Health should consolidate within the Child, Youth, and Maternity Policy work-stream all its efforts to prevent SUDI. Key actions are to develop a SUDI prevention toolkit and to encourage the District Health Boards (DHBs) to develop safe sleeping policies.

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[5]   CYMRC is preparing a special report on alcohol-related deaths, to be published in 2010.

[6]   International comparisons of suicide rates need to be viewed with some caution. Rates across countries are not all comparable because the level of proof that is required for classification of a suicide varies. In New Zealand, reporting data is based on a coroner's investigation. This means, compared to other countries, New Zealand has a low number of "undetermined deaths." In addition, in some countries, reporting of suicides can be deterred due to the stigma associated with suicide.

2.   Drowning prevention (chapter 2)

Any changes in legislation regarding pool fencing should ensure that the risk of drowning is reduced through increased child safety provisions, including provisions to ensure fences remain safe.

3.   Reducing the unintentional injury toll for young people (chapters 2, 3, 4 and 5)

Recognise injury as one of the most important health threats for young people and include it in the health policy agenda, including specific elements related to risk taking. A multi-sectoral approach should occur aiming to build risk competence, life skills and resilience in young people while specifically working to make the environment less hazardous for young people.

4.   Improve unintentional injury information linkage and collection (chapters 2, 3 and 5)

Improve systems to link serious injury data from many sources to provide information on morbidity, which should be used for surveillance, analysis and reporting, to support understanding and to determine priorities for intervention and injury prevention.

5.   Holistic approach with continuity of care (chapters 1, 2, 3, 4 and 5)

The current restructuring of the health system provides an opportunity to better support a holistic approach to child and youth health to increase leadership, collaboration and coordination, with a reduction in service gaps. Services should focus on keeping children and young people the centre of their concerns and working across sectors.

1　Sudden Unexpected Death in Infancy (SUDI)

1.1　Introduction

Sudden infant death syndrome (SIDS) has been defined as 'The sudden death of an infant, which is unexplained after the review of the clinical history, examination of the circumstances of death, and post-mortem examination' (Rognum and Willinger 1995). Controversies associated with the classification of SIDS (eg, deaths in the presence of known risk factors such as cigarette smoke, prematurity, bed sharing or minor infections, where the contribution of the risk factor remains uncertain) have led more recently to the adoption of the term sudden unexpected death in infancy (SUDI),[7] which encompasses both SIDS and these more grey scenarios (Fleming et al 2006).

In New Zealand during the 1980s SIDS rates were high by international standards, and they were not declining, as they were in some other developed countries (Mitchell 1990). As a consequence, a large case control study was commissioned, which found that SIDS was associated with three key risk factors: placing babies on their fronts to sleep, cigarette smoking and a lack of breastfeeding (Mitchell et al 1991). Later, a fourth risk factor, bed sharing, was added, although it was subsequently revealed that bed sharing was of greatest concern for babies exposed to cigarette smoke *in utero* (Mitchell et al 1992, Scragg et al 1995).

The National SIDS Prevention Campaign was launched in 1991 and resulted in a large decline in SIDS mortality during the early 1990s, which was largely attributed to the recommendation not to put infants to sleep in the prone position (Mitchell et al 2007). Although rates for European babies declined markedly, declines for Māori babies were much less marked, possibly as the result of a higher proportion of risk factors other than sleep position among Māori babies (Tipene-Leach et al 2000).

1.2　SUDI numbers and rates from the CYMRC database

1.2.1　SUDI numbers and rates, by ethnicity and gender, 2003–2007

In New Zealand during 2003–2007[8], 328 infants (aged 4 weeks to 52 weeks) died as the result of SUDI. During this period 61.6% of infants dying from SUDI were Māori, 24.4% were Other (including European), 12.8% were Pacific and 1.2% were Asian. Rates for Māori (2.34 per 1000) and Pacific (1.31 per 1000) infants were significantly higher than for Other (including European) infants (0.52 per 1000), while rates for Asian (0.14 per 1000) infants were significantly lower. Mortality rates were similar for males and females, except for in the Other (including European) group, where rates for male infants were 1.9 times higher than for female infants (see Tables 1.1 and 1.2).

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[7]　In some cases of sudden unexpected death, explanations were found, including unrecognised illness or infection, heart rhythm disorders and metabolic disease. In this report these cases have been entered into the sections related to their specific causes. (See the glossary for more detail.)

[8]　Data including 2008 is included in the appendices, which are online at the CYMRC website. 2008 data is not used in this Chapter because some cases are still awaiting the coroner's report.

Table 1.1: Sudden unexpected deaths in infancy, infants aged 4–52 weeks, by ethnicity and gender, New Zealand, 2003–2007

	2003		2004		2005		2006		2007		Total	
	N	**Rate**	**N**	**Rate**	**N**	**Rate**	**N**	**Rate**	**N**	**Rate**	**N**	**Rate**
Total	**61**	**1.08**	**72**	**1.23**	**49**	**0.83**	**85**	**1.41**	**61**	**0.94**	**328**	**1.10**
Gender												
Female	23	0.84	36	0.13	26	0.91	35	1.19	25	0.79	145	0.99
Male	38	1.31	36	0.12	23	0.76	50	1.62	36	1.07	183	1.19
Ethnicity												
Māori	44	2.81	45	2.72	33	1.94	47	2.62	33	1.71	202	2.34
Pacific peoples	4	0.65	8	1.26	7	1.12	15	2.34	8	1.14	42	1.31
Asian	–	–	–	–	–	–	3	0.56	1	0.16		–
Other	13	0.44	19	0.63	9	0.30	20	0.65	19	0.59	80	0.52

Note: Rates are per 1000 live births.

Table 1.2: Sudden unexpected deaths in infancy, infants aged 4–52 weeks, by ethnicity and gender, New Zealand, 2003–2007 combined

Ethnicity	Female		Male		Total			Rate ratio	95% CI	
	N	**Rate**	**N**	**Rate**	**N**	**%**	**Rate**		**LL**	**UL**
Māori	97	2.31	105	2.36	202	61.59	2.34	4.46	3.44	5.77
Pacific peoples	19	1.22	23	1.39	42	12.80	1.31	2.49	1.72	3.62
Asian	2	0.15	2	0.14	4	1.22	0.14	0.27	0.10	0.74
Other	27	0.36	53	0.68	80	24.39	0.52	1.00	–	–
Total	**145**	**0.99**	**183**	**1.19**	**328**	**100.00**	**1.10**			

Notes: Rates are per 1000 live births. Rate ratios compare SUDI rates for Māori, Pacific and Asian infants with those of Other (including European) infants. 95% confidence interval (CI): LL = lower limit; UL = upper limit.

1.2.2 Post-neonatal mortality, by DHB

In New Zealand during 2003–2007 there were regional variations in post-neonatal mortality by DHB. Although much of this regional variation was probably due to demographic variations and the small number of cases involved, post-neonatal mortality rates in Counties Manukau were significantly higher than the New Zealand average, while rates in Waitemata, Auckland, Nelson Marlborough and Canterbury DHBs were significantly lower (see Figure 1.1).

Figure 1.1: Post-neonatal mortality rates per 1000 live births, by DHB of residence, New Zealand, 2003–2007 combined
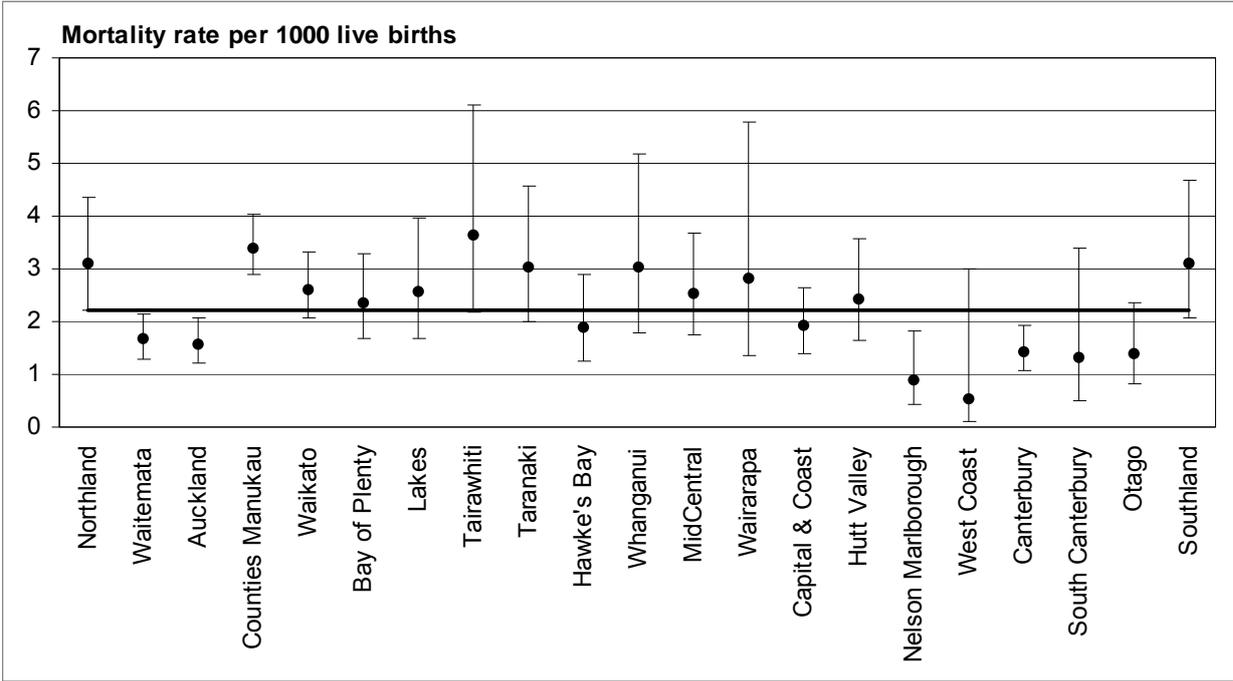
Note: The Exact Method of Agresti and Coull has been used to estimate 95% confidence intervals. The line shows the national post-neonatal mortality rate per 1000 live births.

1.2.3 Post-neonatal SUDI mortality by DHB

In New Zealand during 2003–2007 there were also regional variations in post-neonatal SUDI mortality by DHB. Although much of this regional variation was again probably due to demographic variations and the small number of cases involved, post-neonatal SUDI mortality rates in Northland, Counties Manukau, Waikato and Taranaki were significantly higher than the New Zealand average, while rates in Waitemata, Auckland, Nelson Marlborough and Canterbury DHBs were significantly lower (Figure 1.2).

Figure 1.2: Post-neonatal SUDI mortality rates per 1000 live births, by DHB of residence, New Zealand, 2003–2007 combined
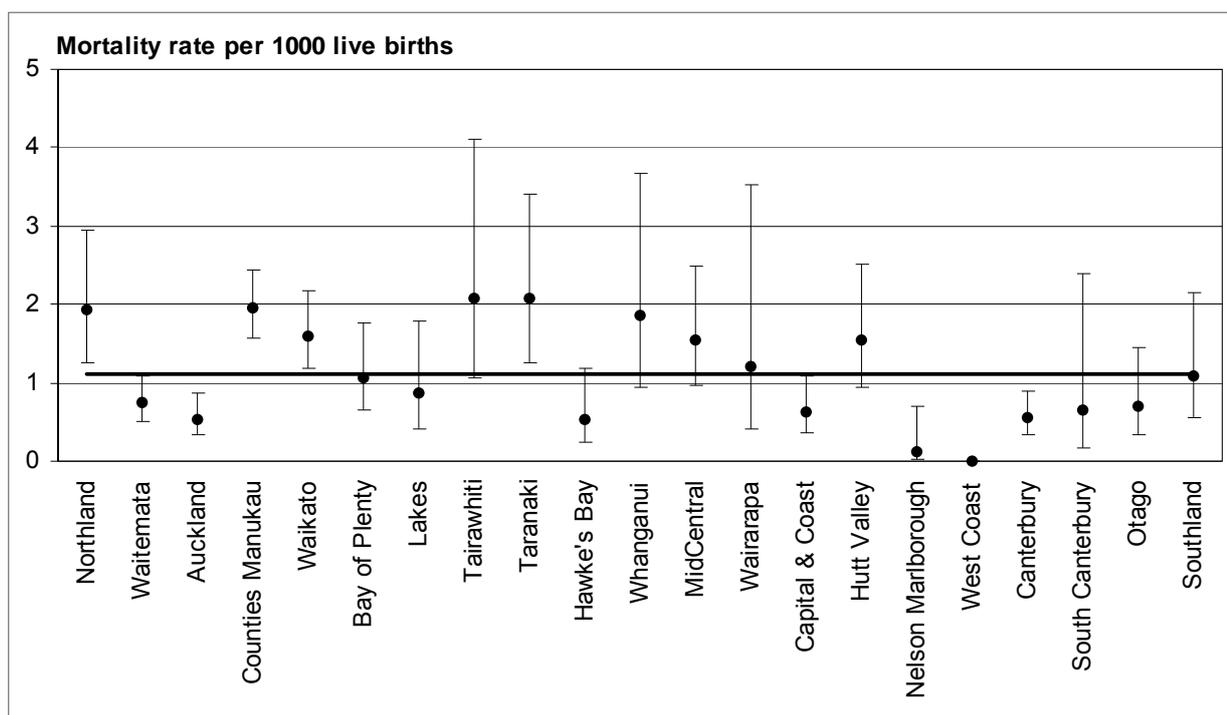
Note: The Exact Method of Agresti and Coull has been used to estimate 95% confidence intervals. The line shows the national post-neonatal SUDI mortality rate per 1000 live births.

1.3 Risk factors for SUDI in the CYMRC database

1.3.1 SUDI deaths, by age

In New Zealand during 2003–2007 there were 359[9] neonatal and post-neonatal SUDI deaths. SUDI deaths were most frequent in infants less than five months of age, with the peak number of deaths occurring at 1 to 2 months (Figure 1.3).

1.3.2 SUDI deaths, by sleep surface

In New Zealand during 2003–2007 there were 154 SUDI cases (43%) where the sleep surface was known to be shared at the time of death. At least 130 of these were infants aged 0-4 months. In 14 (9%) of the shared sleep surface cases the person sharing the sleep surface was not an adult. During this period the number of deaths in infants sleeping on a shared surface (ie, shared with adults or other children) was highest for those less than five months of age. The relatively large number of cases where bed sharing status was not known, however, makes precise interpretation of the proportion sharing a sleep surface at each age difficult (Figure 1.4 and Figure 1.5).[10]

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[9] This includes 31 neonatal (aged 0–28 days) and 328 post-neonatal (aged 4–52 weeks) SUDI deaths.

[10] The Perinatal and Maternal Mortality Review Committee (PMMRC) states in its *Third Report to the Minister of Health* that "of the 11 babies who died in the neonatal period where no obstetric antecedent was present (PDC 11), 10 deaths were associated with unsafe sleeping practices" (2009: 22). The CYMRC and PMMRC have agreed that future SUDI deaths under 28-days outside of a hospital will be reviewed by the CYMRC.

1.3.3 Completeness of SUDI risk factor information in the CYMRC database

In the CYMRC database during 2003–2007 the completeness of information on known risk factors among SUDI deaths varied markedly by condition, with information on preterm birth and low birth weight being relatively complete, in contrast to the high proportion (64%) of missing responses for exposure to cigarette smoke (Figure 1.6).

Figure 1.3: Number of sudden unexpected deaths in infancy (SUDI), by age at death (months), New Zealand, 2003–2007 combined
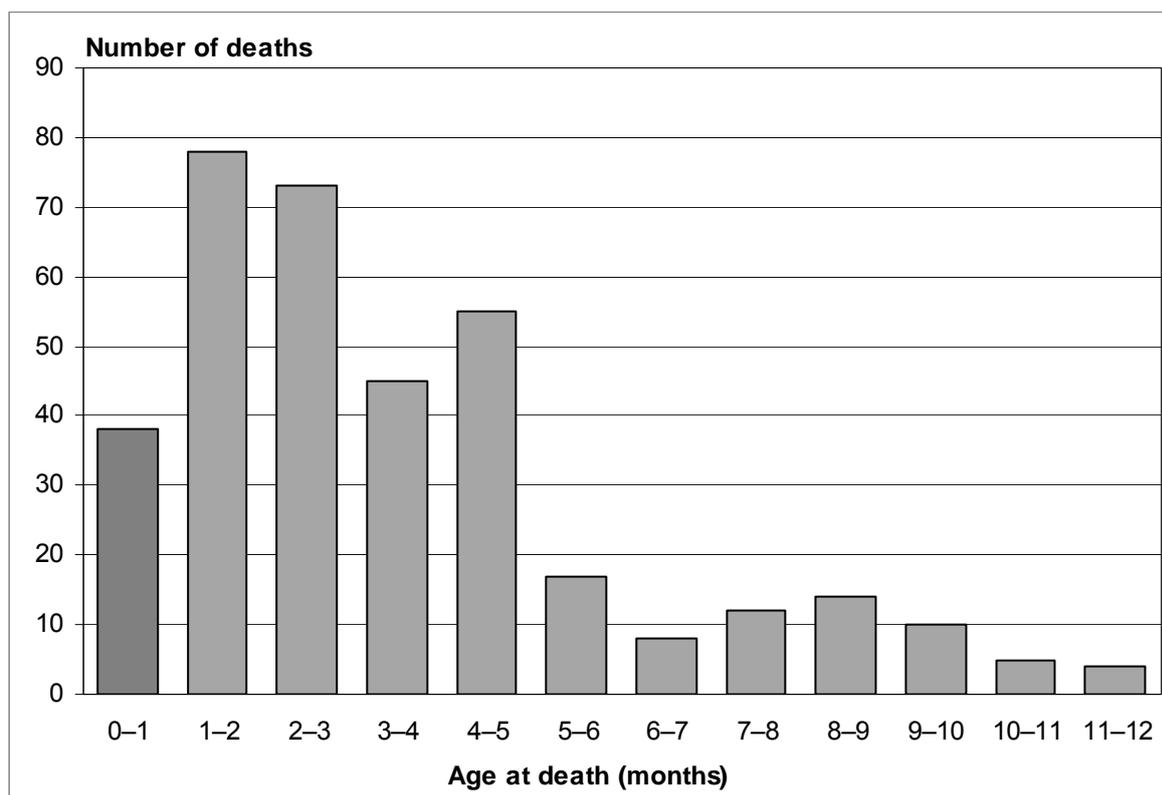
Note: Deaths during the first month include all registered deaths during 2003–2007, plus unregistered deaths known to the CYMRC and Perinatal and Maternal Mortality Review Committee data collection systems.

Figure 1.4: Number of sudden unexpected deaths in infancy, by bed sharing status and age at death (months), New Zealand, 2003–2007 combined
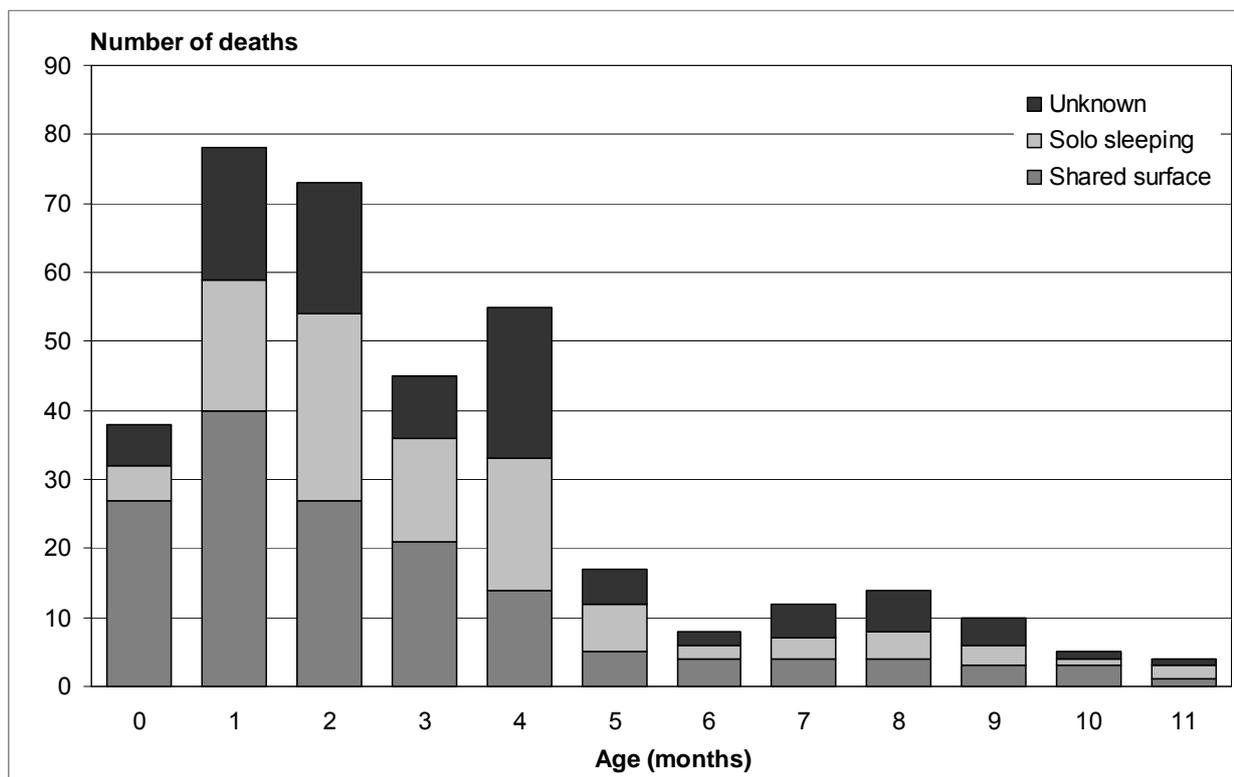
Figure 1.5: Sudden unexpected deaths in infancy rates (per 1000 live births) and bed sharing status in infants aged 0–4 months, New Zealand, 2003–2007
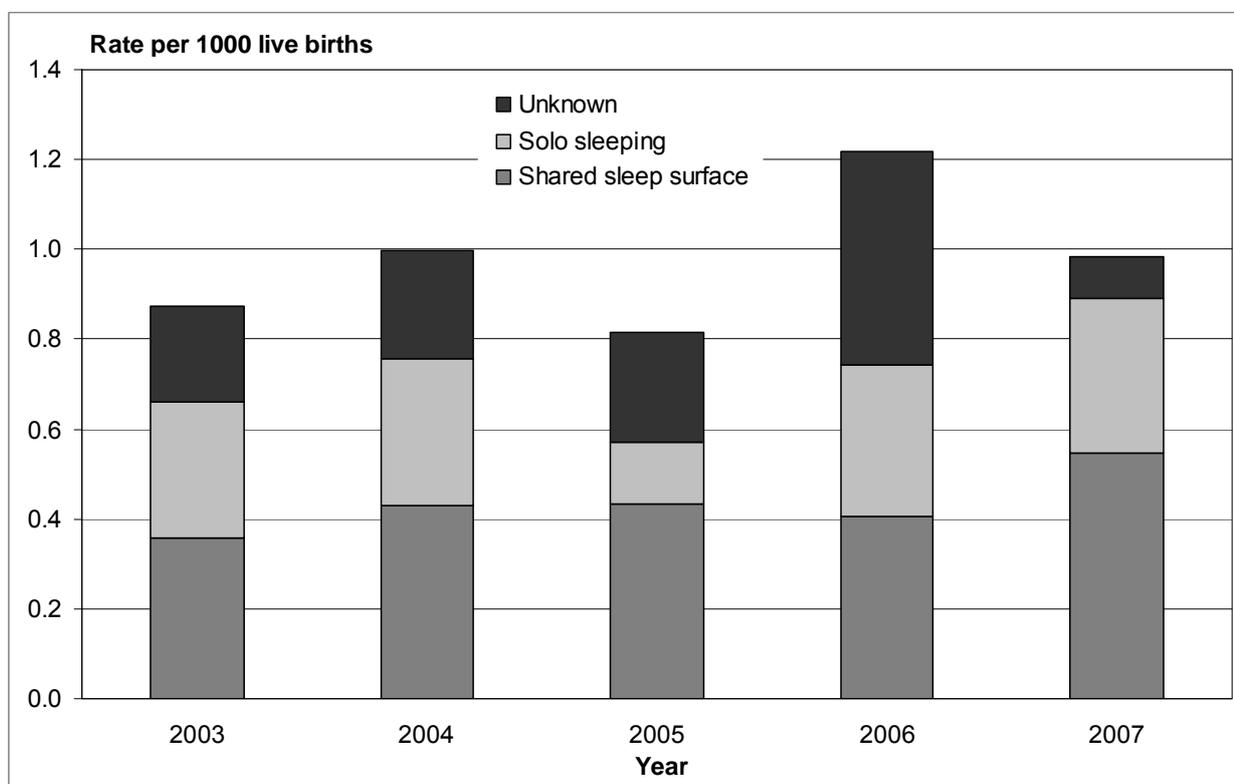
Figure 1.6: Distribution of known SUDI risk factors (including those with missing data) among SUDI deaths, New Zealand, 2003–2007 combined
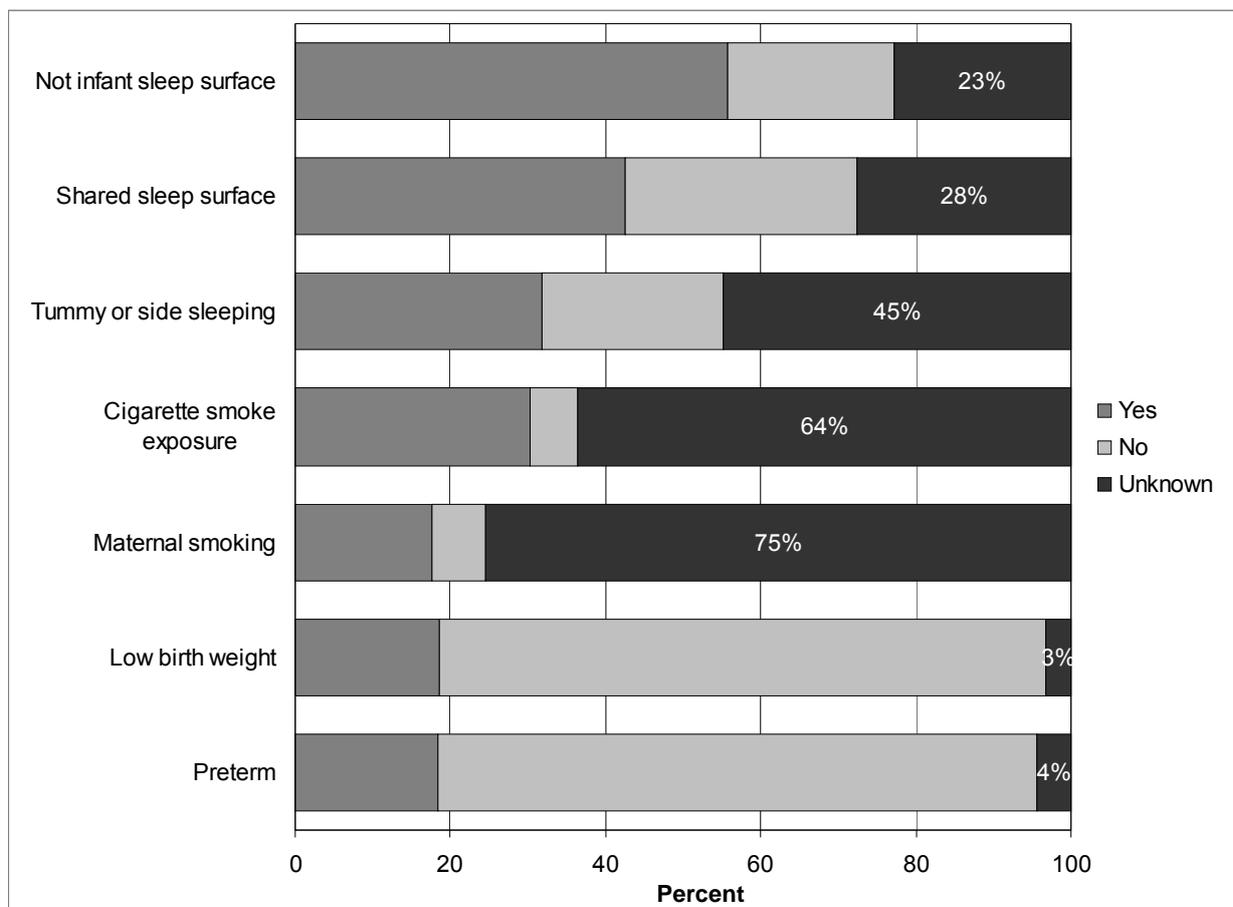
Notes: *Not infant sleep surface*: infant put to bed in a sleeping environment not designed for infants (eg, single/double bed or mattress, couch, chair, car seat, cushion, hammock); *Shared sleep surface*: infant shared a bed with another person (adult or child); *Cigarette smoke exposure:* 1 or more people living in the household smokes; *Low birth weight*: birth weight < 2500 g; *Preterm*: gestation < 37 weeks.

1.4 Local review group recommendations from the CYMRC database

During 2003–2008, a number of recommendations were entered into the CYMRC database as the result of reviews of SUDI deaths by local mortality review groups. Although some of these recommendations applied only to the local setting, a number appeared to be relevant to the national context as well. Many of these recommendations were similar or overlapping, so the list below reflects the general themes that emerged from these reviews.

- **Dissemination and implementation of safe-sleeping messages**. In many cases families were still not aware of or implementing standard SUDI prevention strategies. There was a particular need for greater awareness about providing safe sleeping environments. Specifically, the dangers associated with the following items need to be widely known: using car seats or couches as sleeping surfaces for babies, the use of pillows to prevent babies from moving in their sleep or to prop the head, co-sleeping with adults who have consumed alcohol, or the risk of infants overheating in the co-sleeping environment. The role of Lead Maternity Carers and Well Child providers in providing health promotion advice on safe sleeping (eg, through home visiting, with a review of sleep arrangements) was seen as being crucial, but not all families had a Well Child provider.

- **Reasons why infants have slept in unsafe situations.** As well as lack of awareness, a variety of other circumstances lead to infants sleeping in unsafe situations. Some families were aware of safe sleep practices but as the infant was unsettled a less favourable arrangement occurred apparently contributing to death. For others no safe arrangement was possible because of lack of a cot, household overcrowding or a house that was too cold. At times it was noted that infants normally slept in a safe place but because of a social gathering or parental intoxication an alternative unsafe arrangement occurred. Particular attention needs to be given to ensure safe sleeping arrangements when infants are away from home (eg, visiting grandparents).

  These observations lead groups to recognise the importance of stressing that every sleep must be a safe sleep, whether this is in the hospital, at home, with friends, on the marae or at another gathering of people. Groups recommended that families be better supported in having access to safe sleep spaces, knowledge on methods to settle distressed infants and understanding the need for a sober caregiver. The role of Lead Maternity Carers, Maternity Units and Well Child providers was seen as crucial to ensuring support for families in being ready for the infant birth, ensuring infants have access to a safe sleep space wherever they may be, modelling safe sleeping from birth and providing continuing support to families.

- **Dissemination and implementation of other SUDI prevention messages.** Many of the other known risk factors for SIDS were present among babies who died from SUDI (eg, maternal smoking, prematurity, or socio-economic disadvantage), potentially providing opportunities for (a) the identification of high-risk babies by Lead Maternity Carers and Well Child providers, (b) tailoring SUDI prevention messages (eg, in different languages), and (c) providing more practical support to the caregivers of vulnerable infants. In this context, education on the risk of smoking during pregnancy was seen as being of particular importance.

- **Communication with families and between agencies.** The timely hand-over of care from the Lead Maternity Carer to the Well Child provider, as well as the need to communicate information regarding the infant's potential risk of SUDI, was seen as being crucial. Ensuring that all new mothers have a Well Child provider and General Practitioner, or that there is evidence that such services have been offered but declined, was seen as being particularly important.

- **Support to families dealing with socioeconomic stress.** The identification of, and provision of support to, families under significant social and economic stress was also seen as being of prime importance, with a number of families already being known to social agencies prior to their baby's death, but with resources not being put in place soon enough to assist (eg, families coping with several children in difficult economic circumstances). Where several agencies are involved, it was recommended that one agency be appointed to take the lead in co-ordinating the services the family receive. For some families the high level of support needed was not available even though risks were identified.

- **Establishing a care pathway after the death of a child.** Concern was raised that communication issues after the death of the infant were exposing families to additional stress and/or feelings of guilt at a particularly vulnerable time. In this context, ensuring that the family's general practitioner (GP) has access to the results of post-mortems in a timely manner, and that these results and the cause of their child's death are explained to families in a way they can understand, was seen as being of prime importance. In addition, the use of SUDI death scene investigation protocols by police, and the need for a clear explanation by police of the various procedures required in such situations, was also seen as being important, particularly in cases where additional communication barriers are present (eg, hearing or vision impairment of caregivers). The attendance of a paediatrician or trained health investigator at the death scene was seen as being useful in this context.

To achieve these goals and improve care, establishing a care pathway for families after the death of an infant or child was seen as being crucial (see also Chapter 5). Elements might include a national protocol for investigation (including death scene investigation, and post-mortem performed by a pathologist with the appropriate level of skill), follow-up with a paediatrician, turning off the process of health care so recalls for events such as immunisation or hospital appointments stop, and ensuring families are connected with the appropriate support.

1.5 Approaches taken by the CYMRC to SUDI prevention

1.5.1 Advice to health practitioners

In April 2008 the Ministry of Health and the CYMRC released a leaflet aimed at health professionals, which summarised the current Ministry of Heath recommendations for preventing SUDI. In September 2009 a new leaflet was created by Change for Our Children, with endorsements from the CYMRC, the Ministry of Health's Child, Youth and Maternity Policy team, and the Chief Coroner.[11]

1.5.2 SUDI Referral Advisor

The CYMRC obtained funding for a one-year pilot programme to allow a health trained investigator to work with the Coroner's office to improve information collection for SUDI deaths and to provide support to families that have suffered a SUDI death. The role commenced at the end of 2008. A formal evaluation is forthcoming. Meanwhile, initial feedback suggests it has been a great success for increasing the information available on SUDI deaths. The benefits to families and communities are highlighted in the text written by Barbara Wright. The focus is now looking at evaluation and exploring ways to provide ongoing funding for what seems to be an immensely valuable service. (See also http://www.cymrc.health.govt.nz, *Fifth Report to the Minister of Health: Reporting mortality 2002–2008,* Appendix A10.)

Barbara Wright, SUDI Referral Advisor at the Coroner's Office in Auckland, describes her role:

As I work in the Coroner's office I hear of deaths very soon after they occur. My role is to collect information to better understand and prevent the toll of SUDI. I also have an important role supporting families acting as a navigator to guide them through tragic times.

The process of support in my role is as follows:

I support the family at the mortuary to understand the need for autopsy. This may involve taking the baby to the pathologist. I will enquire if they have had Victim Support and, if necessary, contact them. Some families, especially in close knit communities do not want them. The feelings are that they are not victims and no crime has been committed against them. The baby is certainly innocent.

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[11] This leaflet can be obtained from the Change for Our Children website at
http://www.changeforourchildren.co.nz/files/docs/Safe%20Sleep%20DLE.pdf

At this time I can guide them through the process and need for a funeral director, so that they can have their baby back after the post-mortem as quick as possible. From this point I will leave them for about five days and then contact them again, by telephone, to arrange a visit to their home to have a chat. At this visit I will make sure that they have adequate support and invite them to contact their local representative for SANDS or SIDS New Zealand.[12] At times I may become involved in finding help for other crises that occur as a direct result of the SUDI (eg, relationship and housing issues). Throughout the process, I am also collecting data on the death.

I contact all relevant parties immediately (eg, the GP, Whānau Ora workers, and Plunket) to stop the embarrassing, and at times distressing, contact that may happen if home visits or vaccinations are scheduled, and to help activate support.

I remain in contact with the family throughout the coronial process to give them the information when it comes through and to support their varying concerns during their grief process. As the case inquiry comes to an end, I support the family through an inquest or Chambers and ensure they understand the findings and recommendations. If necessary, I will pick the family up and drive them to the inquest. This is a very emotional and stressful time. They feel blame and anxiety whilst still grieving.

1.5.3 Māori Caucus

Guidance was sought from the Mortality Review Committee Māori Caucus[13] on the development of relevant messages and enablers for Māori women and their whānau. The Caucus met on 30 July 2009 in Wellington specifically to discuss SUDI. The Caucus agreed that SUDI is an issue that requires a collective approach. It was agreed that SUDI messages have not been adequately crafted for Māori whānau and that the messages that target Māori must be culturally appropriate and come with enablers that help families to implement the desired changes.

The changing of some behaviours can make a huge difference in the rate of deaths attributed to SUDI. The changes required are not large, but they pose challenges for individuals and whānau. The Māori Caucus would like to see an opportunity for all providers of services to have workforce development around those actions/activities and messages that are likely to make a difference, eg, around bed sharing, smoking and safe sleeping environments. This is likely to need a change in emphasis with national leadership to reduce the toll from this very preventable condition.

Post mortems are a difficult and controversial issue from a cultural perspective. The Māori Caucus indicated a potential shift in values which may make post mortems easier to accept because of a view to supporting the safety of the next generation. Whānau devastated by a death may find the system threatening, which is not helped by a poor understanding and limited explanations of the post mortem processes.

All those involved after a death need to remember to take a humane approach that supports understanding and gives families time. The Mortality Review Committees have a responsibility to facilitate this process as post mortem is an integral part of mortality review. The Perinatal and Maternal Mortality Review Committee (PMMRC) has developed a resource

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[12] Stillborn and Infant Death Support can be found at http://www.sands.org.nz/
SIDS New Zealand can be found at http://www.sids.org.nz/site/

[13] See Appendix A8 for more information on the Mortality Review Committee Māori Caucus (available online at www.

to better help families understand the need for and process of a post mortem.[14] The local networks established by the Local Child & Youth Mortality Review Group (LCYMRG) process offer a powerful system to allow those involved in after death care to be involved in a shared process of continuing quality improvement. Further work in this area is particularly important to the Māori Caucus. (See the discussion and recommendations on *After the Death of a Child* in Chapter 5.)

1.5.4 Cots for Tots

The CYMRC is of the belief that as much effort needs to be put into ensuring infants have a safe place to sleep as is currently put into having a safe place to ride in cars. For some families financial issues can make getting a cot for an infant difficult. Joint work between CYMRC, Child, Youth and Family (CYF), and Work and Income is focusing on increasing awareness of the vulnerability of unsafe sleeping and on increasing professional awareness of the financial support that is available from Work and Income to purchase a cot if necessary. Information will be passed on to Lead Maternity Carers, Well Child providers, and other professionals working with families.

There is also a development in some Māori communities of a programme which aims to increase the provision of safe sleeping places. A woven flax basket called a wahakura is targeted to mothers who smoked in pregnancy in an effort to mitigate some of the SIDS/SUDI risk of these infants and prevent bed sharing with a parent or caregiver.

1.6   Observations by the CYMRC on SUDI prevention

1.6.1 Observations

Following review of the data contained in the international literature and the CYMRC database, the recommendations made by local mortality review groups and the feedback provided by the SUDI Working Group and the Māori Caucus, the CYMRC makes the following observations.

1.   A substantial reduction in numbers of SUDI in New Zealand is achievable and should be a high national priority. Attention to the needs of high risk Māori infants is paramount.

2.   The importance placed on the safe sleeping of infants, by the community as a whole and families and professionals in particular, needs to increase.

3.   Despite considerable evidence regarding the risk factors for SUDI and consensus on the most important actions needed to prevent SUDI, large numbers of infants continue to die. This suggests that SUDI prevention messages are not reaching families of high-risk infants in a way that meets their needs and/or there are significant barriers to implementing SUDI prevention messages by the caregivers of vulnerable infants.

4.   New approaches to the dissemination of SUDI messages to families with infants at high risk of SUDI need to be developed, with a particular emphasis on meeting the information needs of Māori and Pacific families and those living with significant socioeconomic constraints. Lead Maternity Carers and Well Child providers are ideally placed to disseminate such messages but need to be supported with workforce development and resources. Greater national co-ordination plus the development of informational resources that are particularly targeted to high risk families is likely to be beneficial.

[14]   The PMMRC published a document entitled *Pānui for Post Mortem Examination* in July 2009. It can be obtained from the PMMRC website at http://www.pmmrc.health.govt.nz/

5. To further support families, a range of enablers and other more general forms of support may need to be provided in order to ensure that caregivers are better able to act on current SUDI prevention advice. Examples might include:

   a. Schemes that support all babies leaving hospital having access to a safe sleeping environment. Examples might include cot hire schemes or assistance through LMCs or social workers to access Work and Income funds for a cot purchase,[15] similar to the processes that support babies having an approved car-seat.

   b. Programmes to offer extra support and guidance to vulnerable families who are most at-risk for SUDI, such as support and guidance offered from a respected elder or community health worker with time assigned to spend with the family to reduce risky behaviour and promote safe sleeping practices.

   c. Other enablers developed following consultation with Māori and Pacific people, review of available evidence and extra research as needed.

As a result of these observations the CYMRC makes the following recommendations.

1.7 Recommendations from the CYMRC on SUDI prevention

The CYMRC recommends:

1.7.1 Policy

1. That the Ministry of Health consolidate within the Child, Youth, and Maternity Policy work-stream all its efforts to prevent SUDI. This would provide greater central cohesion and more support for providers to maximise their impact, while also respecting the need for a plurality of approaches.

   Likewise, the funding of Ministry of Health contracts to providers must align with this work-streams' SUDI-related policy goals. Key goals should include:

   a. that the Ministry of Health develop a SUDI Prevention Toolkit, which provides an evidence base for:
      i. messages to prevent SUDI
      ii. enablers of change that are appropriate to the community targeted
      iii. methods of bridging the gap between what is known and what actually happens for infants

      The target audience would be DHBs and health professionals working with families. A special focus should be on what works to support vulnerable families in communities with the highest needs, especially Māori

   b. that lead maternity carers and well child services be required to assess for vulnerability to SUDI, share information and personalise support for families at time-appropriate points during pregnancy and in a baby's first year

   c. systems should be developed to support families better in preventing SUDI and enabling change.

2. That action on smoking cessation, before, during, and after pregnancy, be elevated to a level consistent with its status as a major health concern, especially for Māori and be more clearly linked to prevention of SUDI. DHBs should be required to report the

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[15] If the recommendation for research is followed (item 3 below) it is hoped that a variety of safe sleeping solutions may become available, thereby giving families more choice.

smoking/smokefree pregnancy status of their populations as a requirement of funding agreements.[16]

3. Research into SUDI needs to be targeting to fill knowledge gaps, particularly with regard to safe sleeping environments for Māori babies. There is evidence about unsafe sleeping practices but a paucity of evidence about what represents safe sleeping practices and innovations, as well as what practically works to bridge the gap between what is known about safe sleep and what is done to keep infants safe.

1.7.2 District Health Boards

4. That every DHB implement a safe infant sleeping policy:

    a. for modelling safe sleeping practices in neonatal and postnatal facilities

    b. to ensure safe sleeping arrangements are in place for all babies at every sleep before discharge home

    c. to advise on safe strategies for night feeds and settling infants.

5. That DHBs monitor and report on:

    a. the continuity of care in early infancy between Lead Maternity Carers, hospital services, Well Child providers and general practitioners

    b. the proportion of infants who have a named general practitioner recorded in the National Immunisation Register by four weeks of age (which is one potential performance indicator).

Protecting infants from SUDI[17]	
Babies are safest when they sleep face-up (on the back), with the face clear (plenty of space in front of their face and no pillows), in their own safe sleep space and are smokefree from conception.	
DO	**DO NOT**
Keep baby "smoke free" in the womb and after birth	DO NOT sleep babies in a place where the face can get covered or where they can get trapped or strangled – avoid pillows, soft surfaces, gaps and cords
Sleep babies on their backs on a firm flat surface not propped – any other position increases risk	DO NOT sleep babies in the same bed or on the same surface as adults who are intoxicated or very tired
Breast feed	DO NOT sleep babies in spaces not designed for infant sleep (eg, couches or adult beds)[18]
Sleep babies in a room with parents/caregivers when the parent/caregiver is also asleep	DO NOT over heat or wrap too tight
Risks of SUDI are reduced if babies sleep alone, not sharing a sleeping surface with anyone (adult or child) while they are under three months of age.	
Where infants are more vulnerable,[19] extra efforts are needed to reduce SUDI risks. Always use a safe sleep space that is designed for a sleeping baby (eg, a cot).[20]	

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[16] The new *ICD Code Z58.7 Exposure to tobacco smoke* that came into force in September 2009 could capture this on the Newborn Record.

[17] *Protecting infants from SUDI* is available as a full-page, quick-reference guide on the CYMRC website at http://www.cymrc.health.govt.nz.

[18] Scheers, Rutherford, and Kemp 2003.

[19] Vulnerability is increased if there is exposure to smoking before or after birth, infants are born before 36 weeks gestation, infant birth weight is less than 2500 grams, or there are medical conditions, illness or caregivers are intoxicated with any substance.

Planning ahead for night feeds, unsettled behaviour and social gatherings can prevent any change to unsafe sleeping arrangements – *"keep every sleep a safe sleep."*

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[20] A safe sleep space is a firm mattress, with baby protected from face covering and entrapment and safe from suffocation under a parent or other child. A fact sheet on cot safety is available from:
http://www.consumeraffairs.govt.nz/productsafety/consumerinfo/cots.html#PDF

2 Drowning

2.1 Introduction

New Zealand has a high rate of drowning compared to other OECD countries, particularly the United Kingdom, Europe and North America (Peden et al 2008; Peden et al 2002). The site of drowning usually varies according to age, with infants predominantly drowning in buckets and baths, pre-schoolers in home pools, and adolescents in natural bodies of water, such as rivers and the sea.

Deaths under five are preventable when the double protection of adequate supervision and appropriate environmental safe guards are in place. In the older age groups increased exposure to dangerous water situations leads to a second peak of drowning in the early 20s, despite greater competence in water. In some circumstances risk-taking behaviour in young people also contributes. (See Chapter 3 for further discussion of drowning in this age group.)

Although the number of New Zealand children dying each year as a result of drowning is reducing, these deaths have a significant impact on families (Fenner 2000) and are largely preventable. During 1980–2002 the rates of drowning in 1–4-year-olds and 15–24-year-olds were 6.9 and 5.9 per 100,000 respectively (McDonald et al 2005). The data presented in this report for the period 2003–2007[21] show a substantial improvement to 2.46 and 1.78 per 100,000, respectively (see Table 2.1).

This report does not describe non fatal submersion injuries. Many who survive submersion are severely injured for life with traumatic brain injury through asphyxia. The number of cases of permanent traumatic brain injury arising in childhood from drowning is not clear. The Injury Prevention Unit reports two cases of moderate injury for every drowning fatality (Trotter, Russell, Langley, and Casey 2005).

Despite improvement over the last 20 years, a large proportion of drownings and near drownings could have been prevented. New Zealand needs to take every step possible to reduce the number of drowning deaths and near drowning episodes. The focus of this chapter is on understanding and preventing drowning deaths in those under five years of age, with a special focus on drowning in private pools or baths, which make up 58% of cases for this age group (see Figure 2.2).

2.2 Statistics on drowning from the CYMRC database

Drowning is the second most common cause of unintentional injury death for young people under 25 years in New Zealand.[22] In the five years from 2003 to 2007, inclusive, 108 children and young people between the age of 28 days and 24 years died as a result of immersion in water, at an overall rate of 1.5 per 100,000.

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[21] Data including 2008 is included in the appendices (availablew online at www.cymrc.health.govt.nz). 2008 data is not used for rate calculation because some cases are still awaiting the coroner's report.

[22] Motor vehicle crashes are the number one cause of unintentional injury. See Chapter 3 for more information on unintentional injuries, particularly for older youth, in New Zealand.

Table 2.1: Drowning deaths in New Zealand by age and gender 2003–2007

	Total drownings 2003–2007	%	Rate (per 100,000 estimated population)
All drowning deaths	**109**		**1.47**
Gender			
Male	78	71.6	2.06
Female	31	28.4	0.85
Age category			
Under 1 year	6	5.5	2.05
1–4 years	28	25.7	2.46
5–9 years	15	13.8	1.03
10–14 years	6	5.5	0.39
15–19 years	24	22.0	1.56
20–24 years	30	27.5	2.09
Ethnicity			
Māori	40	36.7	2.42
Non-Māori	69	63.3	1.20
Location			
River	31	28.4	0.42
Beach	30	27.5	0.40
Private pool	13	11.9	0.18
Bath	10	9.2	0.13
Boating	8	7.3	0.11
Lake	5	4.6	0.07
Low volume water	4	3.7	0.05
Pond	3	2.8	0.04
Public pool	3	2.8	0.04
Unknown	2	1.8	0.03

In New Zealand during 2003–2007 the rate of drowning in males was 2.4 times[23] higher than the rate in females (see Table 2.1), and the rate of drowning in Māori was 2.1 times[24] that of non-Māori. Drowning rates were lowest in the 10–14 years age-group (0.39 per 100,000), followed by the 5–9 years age group (1.03 per 100,000), with the highest rate of drowning deaths being in the 1–4 years age group (2.46 per 100,000) and the 20–24 years age group (2.09 per 100,000). This suggests that pre-school children and young adults are at greatest risk of drowning.

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[23] Males are 2.4 times more likely to drown (95% confidence interval CI: 1.6–3.6).

[24] Māori are 2.1 times more likely to drown than non-Māori (95% confidence interval CI: 1.4–3.0).

Figure 2.1: Number of drownings in New Zealand, 2003–2007 combined
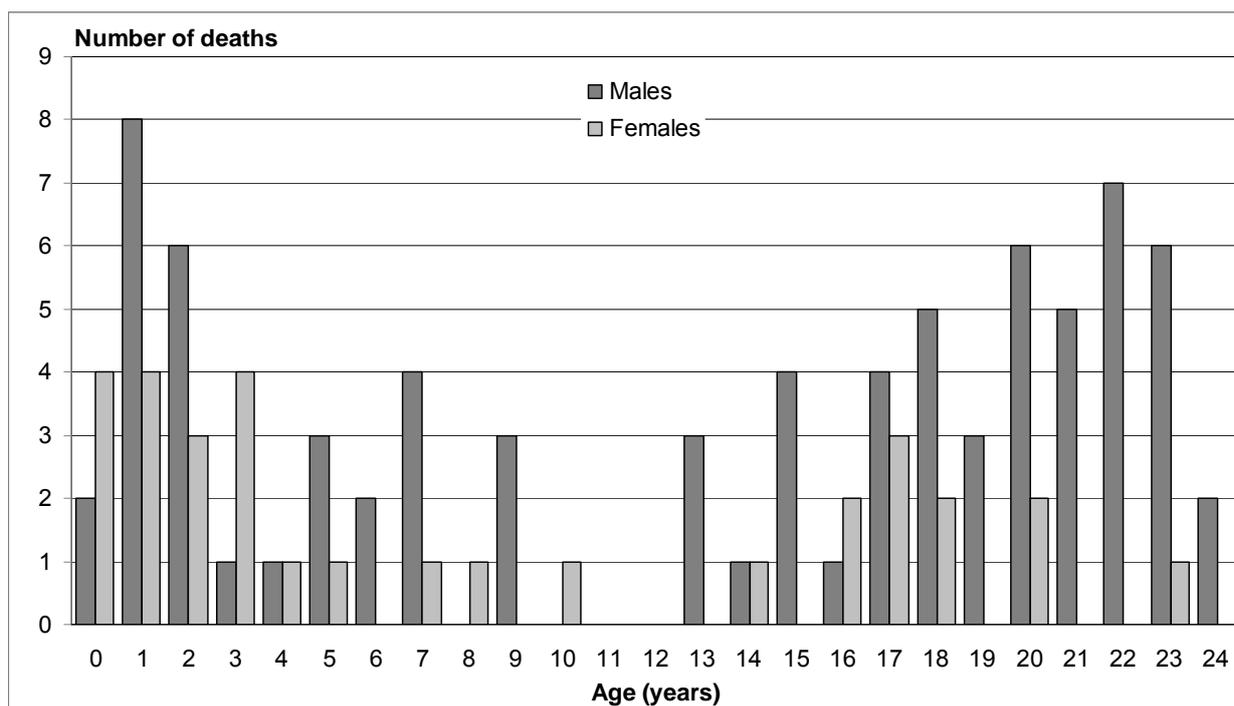
Note: No drownings occurred for the 11 and 12 years age groups during this time period.

The places where drownings occurred have been analysed into the following categories:
- rivers (including all freshwater waterways)
- beaches (including tidal estuaries, harbours and rocky foreshores)
- private pools
- public pools
- baths
- boating (any location, all types of boat)
- lakes
- low-volume water collections (including, but not limited to, buckets)
- ponds.

Children under five years, especially infants, are intensely vulnerable to drowning even in very small bodies of water (eg, a bucket), so a lapse in supervision can be sufficient to allow an infant or child to drown. The double protection of a safe environment and adequate supervision is, therefore, crucial. For older children through to 12 years of age it seems likely that increasing swimming skills and ongoing caregiver supervision contribute to lower rates of drowning.

Drowning in the 15–24 year age group is considered in the next chapter along with other types of unintentional injury in this age group.

Figure 2.2: Drowning, by location and age group, 2003–2007 combined

Age group 0–4 years (34 deaths)
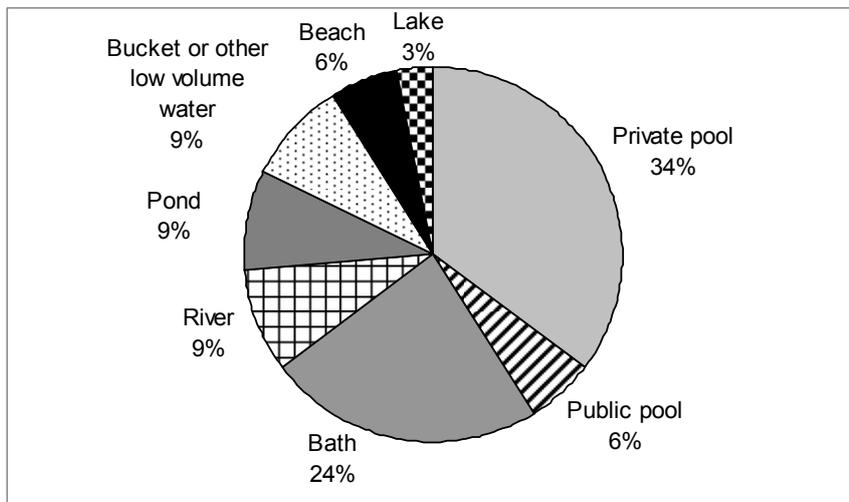
Age group 5–14 years (21 deaths)
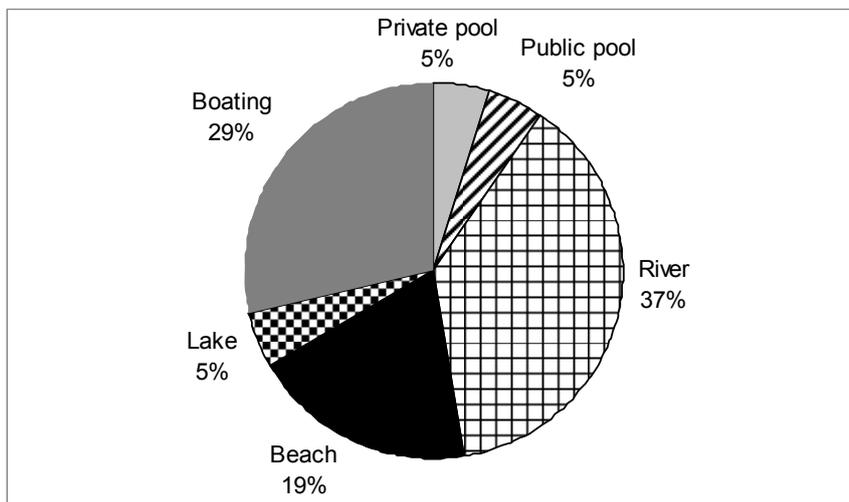
Age group 15–24 years (54 deaths)
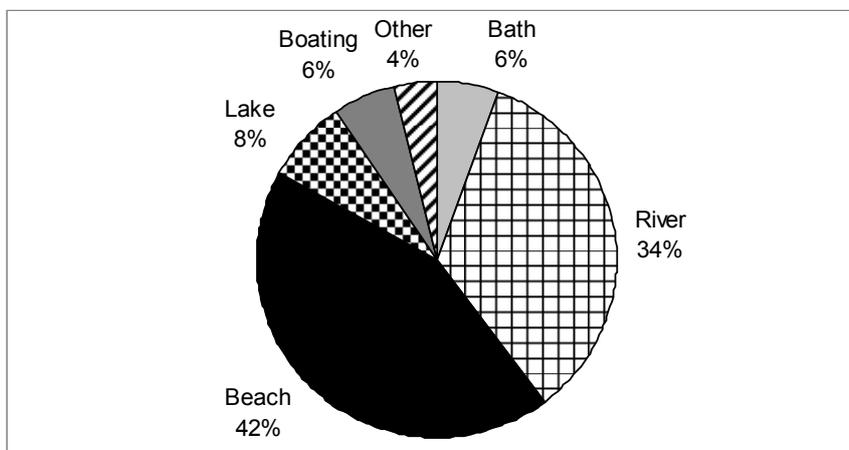
The main locations of drowning for those less than five years of age were private pools (35%), baths (23%), rivers (9%), ponds (9%) and low-volume water collections (9%).[25]

In children 5 to 9 years of age the main locations of unintentional drowning were rivers (47%), boating (27%) and the beach (20%). Locations in which children aged 10 to 14 years drowned were the beach (33%), and rivers, boating, lakes, and public pools (17% each).

2.2.1 Bath drowning[26]

The most common site of drowning in infancy (0–12 months) is the bath. During January 2002 to December 2007[27], nine 1–12 month-olds drowned, with four (44%) of these being in a bathtub. All of these deaths occurred when the infant was left unsupervised by an adult.

Deaths in baths also occur in older age groups, usually in association with a medical condition that predisposes to unconsciousness (such as epilepsy).[28] In the 1–24 years age group, during 2002–2007 (inclusive) there were 10 drownings in the bath. Three were presumed to be intentional (ie, assault) and four were associated with a medical condition. The remaining three deaths were in children aged between 1 and 2 years who were left in the bath without adult supervision.

Parents were often away from young children for a short time, often to attend to another child or to household tasks. Some children were left unattended in bath seats and subsequently fell out. These findings are consistent with other studies, which have found similar reasons for leaving children unattended. Table 2.2 describes the reasons for lack of parental supervision for drowning deaths in Ontario, Canada, from 1986 to 2006.

Table 2.2: Reasons for lack of parental supervision in drowning deaths in Ontario, Canada, 1986–2006

Reason	Number of cases	Reason	Number of cases
Telephone call	9	Answering door	2
Usual practice	7	Attending to other sibling	2
Adult fell asleep	5	Preparing food	2
Chores	3	Outside of home	2
Bedtime preparation	3	Watching TV	1
Unaware of location	3	Smoking	1
Co-bathing	2	Not given	9

Source: Paediatric Death Review Committee and Deaths Under Five Committee 2008

There have been investigations into the possible role of bath seats in drowning in infancy. Although none have been able to confirm that this is a risk factor for drowning, it appears that bath seats give parents a false sense of security, leading to infants being left unattended more frequently (Byard and Donald 2004; Lee and Thompson 2007). The European Child Safety Alliance now recommends that bath seats not be used (European Child Safety Alliance 2006; Peden et al 2008).

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[25] The age groups used in this section (0–4 years, 5–14 years, 15–24 years) were selected on the basis of a commonality of location of drowning within the age range, and are consistent with standard age groups used in injury epidemiology.

[26] The figures in this bath drowning sub-section include some deaths that were presumed to be intentional.

[27] Data from 2002 is included here so these deaths occurred over a six-year period.

[28] The Epilepsy NZ website is http://www.epilepsy.org.nz/main.cfm?id=49

Research has also suggested that parents are more likely to leave a small child in the bath if an older sibling is present (Lee and Thompson 2007). Young siblings are not suitable caregivers for infants and young children in the bath.

The common factor in these drowning deaths was a lack of adult supervision. The table from Ontario gives a frightening insight into how easy it can be for a small child to drown in his or her own home while a caregiver's attention is diverted. Such an insight can be used to help families understand the risks and then plan to avoid them. Professionals need to place more emphasis on educating parents of the dangers of leaving children under the age of three years in the bath, even for a few seconds. If parents need to leave the bathroom for any reason while their child is in the bath, they should take the child with them. When parents are taught to bathe children, this simple strategy to keep their children safe should be taught as well.

2.2.2 Drowning of children in private pools: children under 10 (January 2002–December 2008)[29]

Private pools are the predominant site of drowning in children under the age of five years. Cases of drowning[30] in private swimming pools over the period 2002–2008 were reviewed. Eighteen children drowned in private pools, with an age range of nine months to 4.5 years. Nine were male (50%) and 10 children (56%) were less than two years of age. The mean age of drowning in private pools was 24 months.

Eleven of the pools were in the child's usual place of residence, three were at grandparents', and other cases occurred in a neighbour's pool or while visiting. None of the children who drowned were being directly supervised by an adult at the time.

No information about the way the child accessed the pool was available in one case. The figures below, therefore, relate to 17 cases, all of which occurred in fenced pools. The fences did not comply with the Fencing of Swimming Pools Act 1987 (the Act) at the time of drowning on 12 (70%) occasions. A number of these fences had previously been compliant with the Act, but deterioration of the fence or gate, or modifications to the fence or gate, had occurred, thereby leading to non-compliance. Full information about previous fence inspections and compliance was not available on the Committee's database.

On 10 (59%) occasions the child gained access to the pool via the gate. Eight of these gates were not compliant with the Act. The Act requires gates to be self-closing, open outwards, have a secure child-proof latch and have no gaps around the gate. The non-compliance of gates included problems with all of these requirements. Gate spring and latch failure due to deterioration with time or mechanical blockage of gates or catches were important issues.

On three (18%) occasions the child was able to climb over the fence. Two of the fences climbed were non-compliant with the Act. Methods used to climb the fences included using items such as chairs or toys, or the use of footholds that were present in the fence. On four (24%) occasions the child gained access through the fence where the fence was defective (eg, a hole in the fence, non-standard fence, or the fence was arranged in a non-secure way).

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[29] For private pool drowning a seven-year period data collection – from the start of collection in January 2002 until the end of 2008 – was used for analysis.

[30] Cases have also been included where death was not immediate but occurred later as a direct result of the injury sustained through near drowning.

In some of the pools the water was heavily colonised with algae. Disused pools are just as dangerous to children and discoloured water may make the hazard less obvious and create difficulties knowing a child has fallen in. Drowning occurred in every season of the year. December was the commonest month for drowning, with five cases. Ten children drowned in the three summer months, with four in spring and three in autumn.

Data on the number of cases of permanent traumatic brain damage from near drowning in private pools was not available.

2.2.3 Discussion: Swimming pool fencing

In the seven years prior to the Fencing of Swimming Pools Act 1987, 74 children drowned in private pools (McDonald et al 2005). The data in this report is consistent with the continuing decline of drowning in private pools since the Act came into force. Over the seven-year period reported here, 18 children drowned, or 2.6 per year on average, compared with 11.5 per year prior to the Act (Department of Building and Housing 2008), despite a greater than 30% increase in pool numbers.[31] These improvements highlight the benefits of using a mechanical barrier in addition to the expectation of constant supervision (double protection) to prevent drowning in infants and young children.

The complete lack of a pool fence was not a contributing factor in any of the 18 cases. Seventy percent of the fences were not compliant with the Act at the time of the drowning. Mechanical deterioration, structural modifications and layout changes made over time had presumably rendered a number of compliant fences non-compliant. It is assumed, but not certain, that all the fences would have been compliant when first constructed. No mention is made in the police or coroners' reports of the pools having been constructed without the awareness of local territorial authorities.

An additional risk related to pool fences is that ongoing modifications and structural changes are frequently made to houses. Changes of ownership also occur, so the current owner may have no awareness of the original compliance process.

It seems that the current systems have failed to protect a number of children because there is variable monitoring of ongoing compliance with the Act. The situation could be compared with cars having a warrant of fitness when first registered and then assumed to be mechanically sound and safe forever more. Clearly this does not occur for either cars or pool fences. Cars have a regular monitored system to ensure safety. Similarly, the responsibility of owning a dog is enforced by annual licensing, and most local authorities use this as an opportunity for education and updates. In 2007 a survey was sent to 73 local authorities regarding compliance with and enforcement of the Fencing of Swimming Pools Act. Of the 49 returned questionnaires, only 31 had a programme of re-inspection of swimming pool fences (Gulliver et al 2009). The authors concluded "in order for pool fencing legislation to be effective, enforcement must be maintained" (Gulliver et al 2009: 132).

A regular system of checking pool fences offers not only a chance to check the fence for mechanical soundness but also a chance for some safety-related education and reminders. Checking could occur via regular visits, random visits, a mail-based questionnaire checklist process and information sharing, or a combination of these. Checks and reminders in spring would offer the best chance of pools being safe and adult supervision being in place for the spring and summer, when the greatest risks arise. Encouraging households to perform a pool

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[31] This is based on a January 2007 study by the University of Otago's Injury Prevention Research Unit into the compliance and enforcement of the Fencing of Swimming Pools Act 1987, commissioned by Water Safety New Zealand. The study estimated 16,600 new pools were constructed in the last 10 years from data provided by territorial authorities (Gulliver et al 2009).

fence check at a fixed time in relation to a seasonal event, such as the clocks going forward for daylight saving (as happens for smoke alarms), is a strategy that could be considered.

2.3 Local review group recommendations: drowning in under five-year-olds

Over the 2003–2008 period a number of recommendations were made by local mortality review groups to the CYMRC national committee as a result of reviews of these drowning deaths. A number of these recommendations were relevant nationally, and the following list contains common themes that emerged from local reviews.

- There was concern that infant bath seats engender a false sense of security in parents, and it was recommended that this be investigated further.

- It was recommended that there be more education on the water safety sections of the Well Child book, particularly by Well Child providers.

- It was recommended that parents undertake an audit of safe play areas, particularly to identify water hazards in the children's normal play area. Water Safety New Zealand provides a checklist.

- Concerns were raised about the lack of ongoing maintenance of pool fences and the lack of checks for ongoing compliance.

2.4 Approaches taken by the CYMRC to drowning prevention

In response to the concerns raised during the process of data collection and death review, a number of CYMRC agents at the national and local level have taken steps to prevent drownings. Following the publication of the CYMRC report in 2005, safe bathing messages were placed into the Well Child book. Plunket added safety messages into their programme after local mortality review group and CYMRC action. The CYMRC has also advocated for changes to the Fencing of Swimming Pools Act 1987 to ensure pool fences remain compliant. To this end, it made a submission to inform the Department of Building and Housing's 2008 review of the Act.

Some overseas studies have suggested that for every child who dies from drowning, up to an equal number will be left with brain damage that may result in long-term disabilities, including memory problems, learning disabilities and permanent loss of basic functioning and vegetative state.[32] Traumatic brain injury in infancy and childhood can result in substantial expenses to ACC over the life course – up to $20,000,000 per case.[33]

The CYMRC has been unable to obtain information on the burden of traumatic brain injury from non-fatal submersion. As discussed in the systems issues section of this report (Chapter 5), death is often the 'tip of the iceberg' of suffering, injury and cost. To ensure appropriate priority is given to preventive efforts it is important to consider morbidity from non total submersion as well as mortality. Collecting morbidity information could be a function of a system that links data about serious injuries to improve surveillance, analysis and reporting. (See also Chapter 3.)

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[32] As an example, see Shepherd SM, Shoff WH. 2009. *Drowning*. URL: http://emedicine.medscape.com/article/772753-overview

[33] Jan White, ACC CEO, in speech to Health Select Committee on 19/8/2009.

A local swimming pool inspection programme
by John Symons, Swimming Pool Safety Officer, Hastings District Council

The Hawke's Bay local review members decided to advocate for better swimming pool compliance. At the encouragement of the local review group, the Hastings District Council kicked off the swimming pool inspection programme in 2002. Initially the programme involved searching the individual property records for any sign of a swimming pool (either a historical citing from council staff or an issued building permit/consent) and compiling a swimming pool register based on those findings. A council employee then went through the latest available aerial photographs and looked for any pools that were not registered. Finally, the same researcher used Google Earth to look at the rural areas where there were either no aerial photos available or where the photos were of poor quality.

Once the register was completed, a letter was sent to all the property owners concerned. The letters included a self-assessment questionnaire. From those assessments that were returned, pools deemed in need of immediate inspection were prioritised (ie, pools that were either unfenced or poorly fenced were looked at first). Just over 2800 letters were sent out. Property owner responses indicated that over 900 of the pools had been removed at some stage over the years. This was significant because it is essential for a local authority to have an accurate list of the pools in its area. Since 2002 better-quality aerial photos have become available, and with new pools being built the register now records just over 2500 pools.

Pools are inspected according to priority and owners are given up to four weeks to rectify any non-complying aspects. The inspectors use a one-page self-carboning checklist with enough space to write appropriate comments. The top copy is given to owners on site so they immediately get a report on what needs attention. The carbon copy is scanned onto the property file (ie, digital property records). The site report advises property owners to drain non-complying pools immediately. Follow-up inspections are ideally scheduled at the time of the first inspection; if no one is on site, a reinspection letter goes out with a date and time. Digital photos of the pool fences are taken and attached to the property records.

Once a pool is passed it is reinspected every three years. All inspections are scheduled 1 to 2 weeks ahead by letter. The inspection programme is funded by a levy on the rates, currently $39 per year. A small portion of the costs (approximately 10%) comes from the general rate. The levy covers the costs incurred by the council in carrying out up to two site visits/inspections in every three-year cycle. If additional inspections are required, the property owners are charged a flat fee of $112.50 ($100 + GST). This gives property owners an extra incentive to get the work done quickly. Persistent non-compliance is dealt with via additional inspection fees. To date, no one has been prosecuted under the Fencing of Swimming Pools Act 1987 as a result of this programme. The programme currently has a compliance rate of 95%.

2.5 Recommendations by the CYMRC on drowning prevention

2.5.1 Legislation

1. The current pool fencing legislation has worked well to reduce child drowning. Any changes in legislation regarding pool fencing should ensure that the risk of drowning is further reduced through increased child safety provisions.

2.5.2 Policy

2. Local authorities should consider where systems to support ongoing compliance with the legislation on pool fencing and overall pool safety can be improved.

3. Information on the burden of disease from traumatic brain injury arising from non fatal submersion should be collected to support the prioritisation of intervention(s).[34]

2.5.3 Good practice

4. Those with a medical condition that predisposes them to unconsciousness (such as epilepsy) should be advised to shower rather than take baths.

5. When new caregivers are taught to bath their babies, a simple safety strategy should be taught: 'if you leave the bathroom, take your baby/child with you'.

Community messages

- Never leave children, especially those under five years of age, unsupervised near water, including baths, buckets and water troughs.

- All children under the age of three years should be constantly supervised in the bath by an adult. "If you leave the room, take the child with you."

- Bath aids or young siblings are not a replacement for adult supervision.

- The safety and security of pool fences should be checked regularly, with special attention paid to the gate, which should open outwards and close automatically, with the catch fastening firmly.[35]

- Check pool fences for gaps to crawl under, or for loose bars or planks.

- Never prop open a pool gate or have anything nearby that might block the catch (eg, clothes or towels).

- Never leave chairs or toys so that children can use them to climb over a pool fence.

- If fences are modified or houses redesigned, always check the pool fence still functions to keep children safe.

- Be especially careful with children if you are visiting someone with a pool. If you are in a group, always make sure it is clear who has the job of watching the children; otherwise everyone may assume someone else is watching them.

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[34] This could be part of an improved system that links serious injury information for surveillance, analysis and reporting as recommended in Chapter 3 and discussed in Chapter 5.

[35] Local councils can provide more information on this. See http://www.watersafety.org.nz/pdfs/booklets/Be%20PoolSafe%20Booklet.pdf

3 The Risk Taking Years – Unintentional Injury in Young People

3.1   Introduction

New Zealand youth face significant threats to their health and wellbeing. After the relative safety of the middle years of childhood, rates of death increase dramatically from the age of 14 onwards, especially for young men (see Figure 3.1). This change coincides with young people becoming more independent from their parents, spending more time away from home, being exposed to more dangerous situations and taking more risks. Between 15 and 24 more than two thirds of fatalities are due to injury (see Figure 3.3) including both intentional injury (considered in Chapter 4) and unintentional injury, which is considered in this chapter.

Figure 3.1:   Unintentional mortality rates, by age and gender, 2003–2007 combined[36]
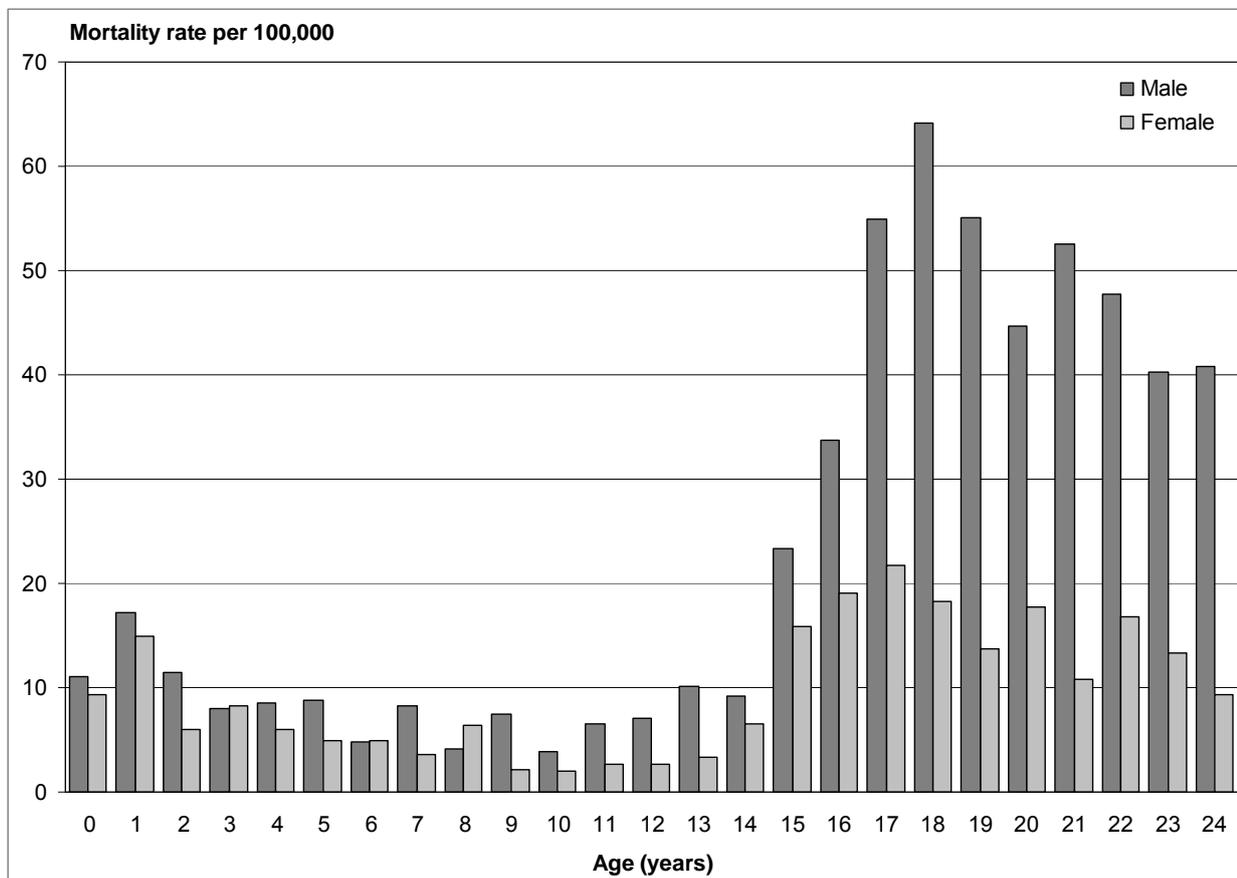
Injury also contributes substantially to morbidity rates and life long disability. While accurate routinely collected mortality data is presented in this report similar data reflecting the burden of morbidity from injury is not routinely available. It has, however, been reported that for 15–19-year-olds there were six serious injures and 17 moderate injures for each motor vehicle related fatality (Trotter, Russell, Langley, and Casey 2005). The improved collection and linking of data would further support efforts to understand, prioritise and prevent injury.

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[36]   Data including 2008 is included in the Appendices (available at www.cymrc.health.govt.nz). 2008 data is not used in this chapter for rate calculations because some cases are still awaiting the coroner's report.

A high proportion of the unintentional injury mortality among young people is due to risk-taking[37] and experimentation that are a normal part of growing up, as is argued by Dr Simon Denny in the box entitled 'Why young people take risks'.

Why young people take risks
by Dr Simon Denny, youth health physician at Kidz First Children's Hospital in Auckland

Young people need to take risks. It is an important part of growing up and learning from new experiences. Adolescents need to discover their own strengths and weaknesses in a variety of different situations, not only to experience success but to learn to cope with adversity and defeat (Konopka 1973). Ongoing research suggests that remarkable changes occur in the brain during the teenage years and into early adulthood. Specifically, between childhood and adulthood the 'wiring' of the brain becomes more complex and more efficient, especially in the brain's prefrontal cortex. The prefrontal cortex is responsible for skills such as impulse control, planning and focusing attention. It is thought that these neurobiological factors may underlie some – but not all – of the reasons that young people take risks.

Although this new research on brain development shows that the frontal lobe is still developing through the teen years and into the early 20s, young people have the same cognitive ability as adults in terms of understanding the consequences of risky behaviours. Research studies have shown that young people have similar abilities to adults in terms of understanding hypothetical situations and logical reasoning from about the age of 13 years upwards (Millstein and Halpern-Felsher 2002). This suggests that young people can understand the risks but are more willing to disregard the risks associated with their choice of action.

Risk-taking during adolescence, therefore, needs to be understood from a wider ecological framework, acknowledging the social, physical and emotional environments in which young people live. For example, laboratory studies of simulated driving have shown that there are few differences between older adolescents and adults in crash rates when tested while driving alone, but when young people are tested while driving with peers in the room their rates of crashes are more than doubled (Gardner and Steinberg 2005). This is also seen in real-life crash statistics, where crash rates are higher when young people drive with peers and increase with the number of passengers in the car (Chen and Baker 2000). The findings of these studies imply that risk-taking during adolescence is also embedded within the social and emotional environments young people find themselves in. This means that while risk-reduction driver education may be feasible, education alone will do little to reduce youth risk-taking in the absence of a wider social-developmental approach.

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[37] Risk taking is defined as active voluntary behaviours associated with heightened risk of injury or death such as reckless use of alcohol, motor vehicles or natural hazards. Different types of risk-taking behaviours tend to cluster.

Risk taking often has other adverse health consequences such as alcohol and drug dependency, unsafe sexual activity, violence, and driving under the influence of drugs or alcohol. These behaviours can have far reaching social consequences such as poor educational performance, unwanted pregnancy and criminal behaviour which impact on more than one generation (OECD 2009a). The OECD has suggested using the birth rate to mothers age 15–19, the number of 15-year-olds who smoke regularly and the number of 13–15-year-olds who report having been drunk more than twice as indicators of the level of risk taking in a community. Rates of youth suicide, death from motor vehicle injuries, unplanned pregnancy and drug and alcohol use in New Zealand continue to be among the highest in the Western world (Ministry of Health 2002; OECD 2009b). Overall New Zealand was ranked 24th out of 30 countries for risk behaviours (OECD 2009b).

Furthermore, alcohol use contributes to the high rates of death by injury, including motor vehicle deaths, suicide, poisoning and drowning. Almost one-quarter of adolescents have recently been in a car driven by someone who was potentially drunk (Adolescent Health Research Group 2008a: 29). Alcohol is the most common drug used by New Zealand youth, and binge drinking puts youth at risk for a number of poor outcomes. CYMRC has commissioned a separate report on alcohol related deaths which will be published in 2010 and will give clearer information on the associations between alcohol and injurious death.

3.2   Statistics on unintentional youth mortality from the CYMRC database

The increase in rates of death from the age of 14 onwards is largely due to increasing rates of unintentional injury and suicide during that time of life. As Figures 3.2 and 3.3 show, transport is the most common cause of death from unintentional injury. Slightly more than 70% of unintentional deaths were the result of a transport-related event. This represents an average mortality rate of 11.09 per 100,000 over the 5-year period.

Over the period 2003 to 2007 62 young people (age 15–24) died of poisoning at a rate of 2.10 per 100,000. Poisoning caused 7.1% of unintentional deaths in this age group, which is a similar proportion to that reported in European countries (Kumpula, Heli and Paavola, Meri 2008). Poisoning often occurred in the context of risk taking and experimentation. As in Europe, alcohol features strongly in New Zealand deaths. (Further analysis from the CYMRC on alcohol related death will be available in 2010). Death from poisoning also occurred as a result of drug abuse, pharmaceuticals, inhalation of hydrocarbons and pesticides. More detailed analysis of poisoning cases in New Zealand is required.

Figure 3.2: Unintentional injury mortality (rate per 100,000), by age group and injury type, 2003–2007 combined
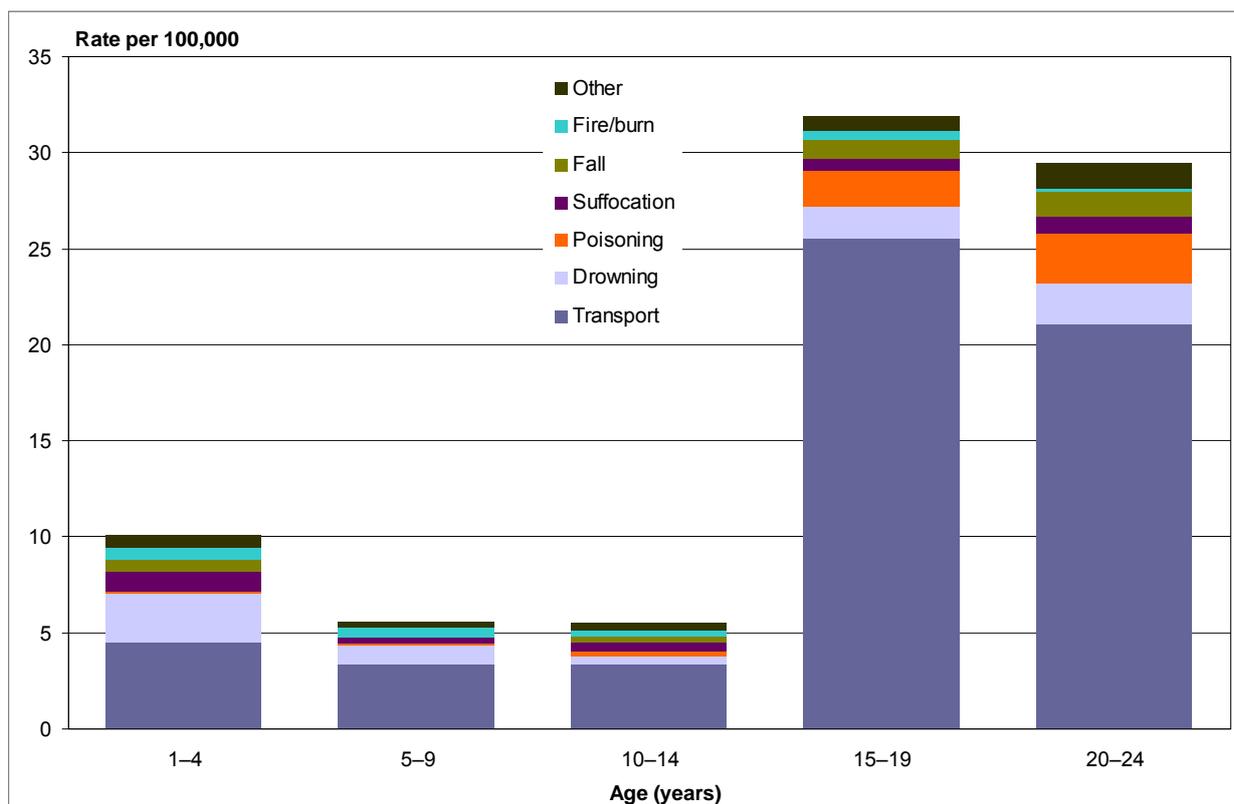
Note: 'Other' includes: adverse effect of medical treatment, cut/pierce, firearm, fall, natural/environmental/animal, struck by/against, or electrocution.

Drowning is the third most common cause of unintentional injury death in the age group 15 to 24 years with 54 deaths during the period 2003–07 (a rate of 1.82 per 100,000) making up 6.1% of unintentional injury deaths.

In young people aged between 15 to 19 years, rivers were the major site of drowning (54%) with a further 33% drowned at the beach. In the 20–24 year age group, 55% occurred at the beach; 17% were river-related, with boating and drowning in lakes accounting for a further 10% each (see Chapter 2 Figure 2.2).

The highest rate of death from drowning occurs in the 1–4 year olds. After a lower rate in the 5–14 year age group the drowning rate increases again in the 15–24 year group (see Chapter 2 Table 2.1, Figure 2.1 and Figure 2.2). The increased rate of drowning after age 13 occurs despite increasing physical ability, strength and swimming skills. This trend and its causes need further analysis. However, it seems to reflect increasing exposure to risky situations, as in surf and rivers, less supervision and poor perception of risk, including some deliberate risk taking, together with the influences of drugs and alcohol (McDonald et al 2005).

The relationship between drowning and swimming skills is complex and may include a trend for good swimmers to take risks that poor swimmers would never consider (Brenner et al 2003). Future work of the CYMRC is needed to explore these issues, especially drowning at beaches and in rivers, as well as the reasons for ethnic disparities in drowning rates (see Chapter 2 Table 2.1).

As illustrated in Figures 3.3 and 3.4, transport related deaths make up the vast majority of injury cases in this age group; therefore, the rest of this chapter focuses on transport.

Figure 3.3: Cause of mortality in youth aged 15–24 years (%), by category of death, 2003–2008 combined (2366 deaths)
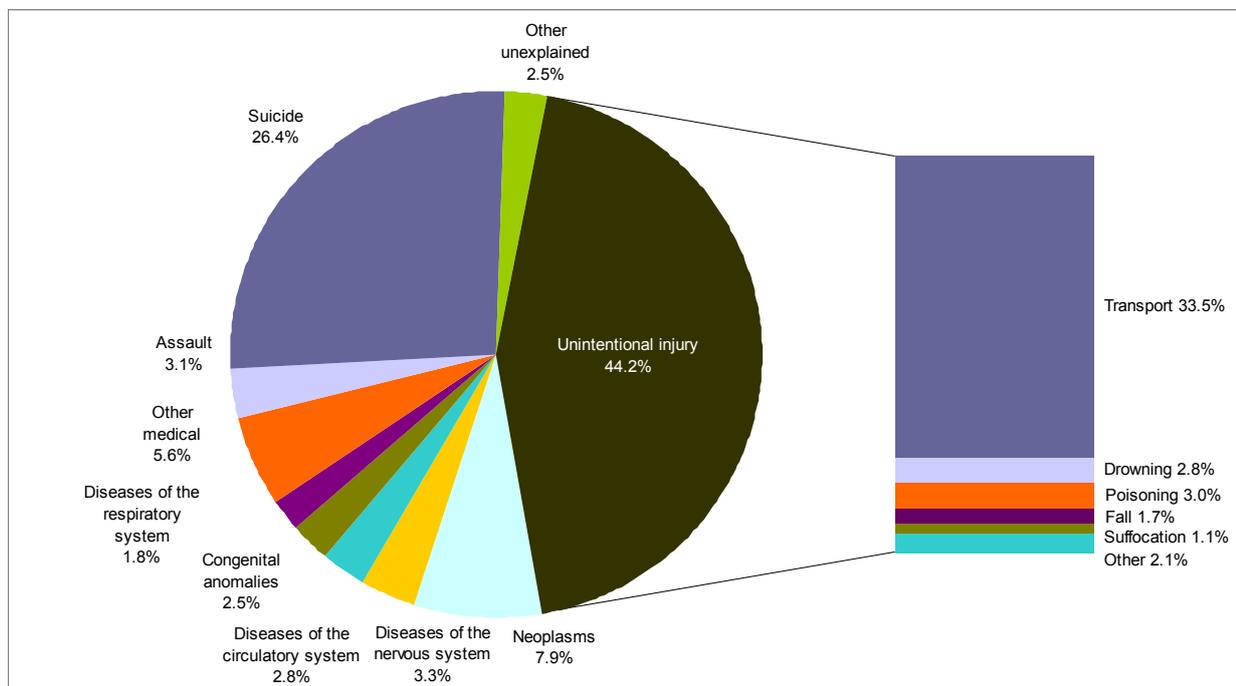
3.3   Statistics on transport mortality

Motor vehicle crashes are the leading cause of death for young people in New Zealand. Table 3.1 based on the CYMRC data shows the mortality rate for males in transport-related events (15.31 per 100,000) is more than twice the rate for females (6.71 per 100,000), and the Māori rate (17.50) is almost double the non-Māori rate (9.25).

Over the five years reported, on average, 165 young people aged 15–24 years died on New Zealand roads each year while more than 4000 sustained non-fatal injuries. In comparison to EU-countries, New Zealand has high rates of young people dying from motor vehicle crashes (Ministry of Transport 2004; Kumpula, Heli and Paavola, Meri 2008). Young people account for 14% of the total population but make up almost 33% of all motor vehicle crash deaths (Ministry of Transport 2008). The majority of young people who die in motor vehicle crashes are male (75%). Although only 25% of deaths are female, young women are more likely to die in a motor vehicle crash than older women (Ibid). The societal cost of motor vehicle crashes was estimated to be $1.1 billion in 2007, which is approximately 10% of the total health expenditure in New Zealand (ibid). From a public health perspective, motor vehicle crashes are among the most serious issues facing young people (National Research Council et al 2007).

Table 3.1: Summary of transport deaths, ages 0–24 years, 2003–2007

| | Deaths | | | | | | | Avge rate |
	2003	2004	2005	2006	2007	Total	%	
	178	173	178	142	176	**847**	-	**11.77**
Gender								
Male	125	115	134	97	126	597	70.48	16.32
Female	53	58	44	45	50	250	29.52	7.07
Age category								
Under 1 year	-	4	-	1	2	7	0.83	2.47
1–4 years	10	9	14	6	10	49	5.79	4.49
5–9 years	9	11	10	12	7	49	5.79	3.42
10–14 years	12	6	12	9	13	52	6.14	3.63
15–19 years	83	86	89	63	73	394	46.52	27.51
20–24 years	64	57	53	51	71	296	34.95	20.66
Ethnicity								
Māori	60	55	64	58	50	287	33.88	19.06
Non-Māori	118	118	114	84	126	560	66.12	9.85

Figure 3.4: Transport mortality rates, by age and gender, 2003–2007 combined
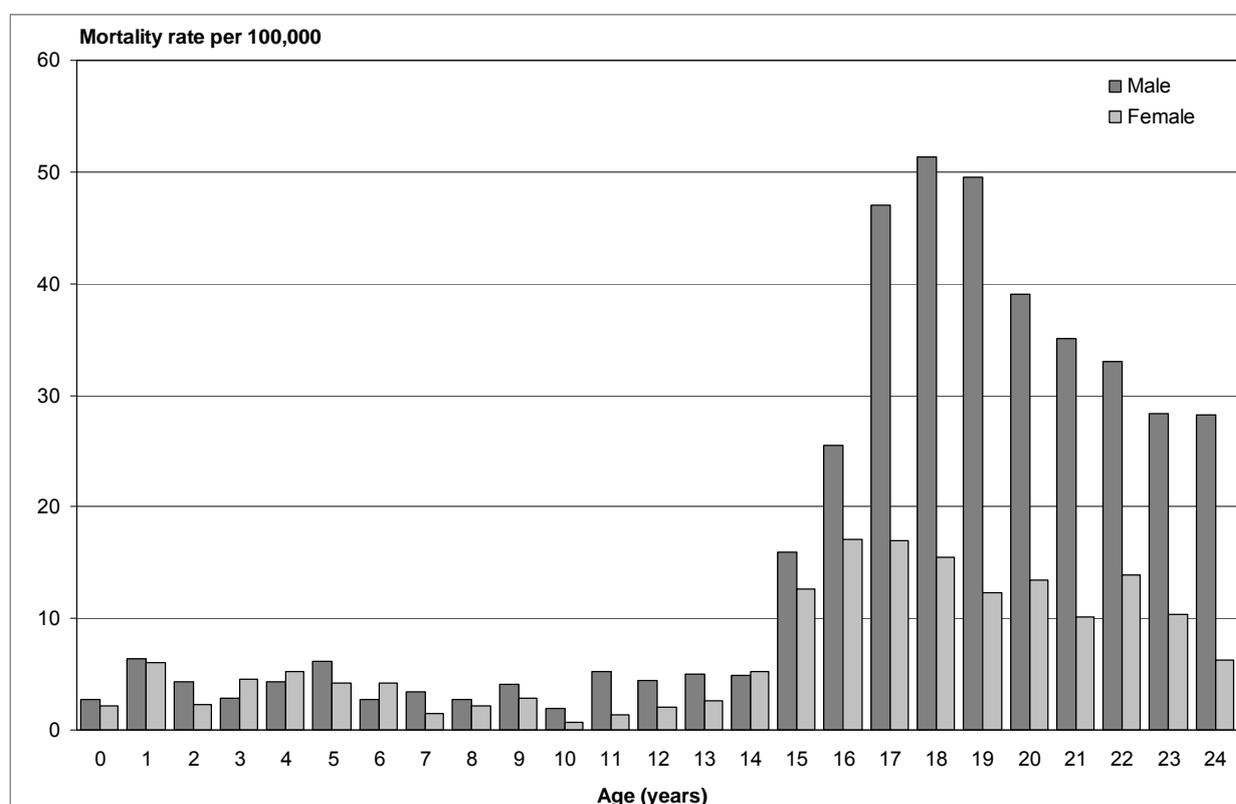
Note: As transport is the major contributor of unintentional injury deaths, Figure 3.4 shows a similar pattern to Figure 3.1.

A closer look at the differences in the death rate between males and females, by age in years, for the five years 2003 to 2007 combined, reveals that:

- males between their 17th and 20th birthdays have the highest rates of death
- 16- and 17-year-old females have the highest rates of death for females

- the rate of death for 18-year-old males is 2.75 times higher than the rate for 17-year-old females

- the rate of death for 24-year-old males is four times higher than the rate for 24-year-old females.

Another interesting finding is that there has been an increase in the death rate of 14-year-olds, yet this is an age when young people are not legally allowed to drive motor vehicles. According to the CYMRC data, of the 16 transport-related deaths of 14-year-olds, 38% (six) were *driving* either a car or motorcycle, and 44% were passengers in motor vehicles; 43% of the passengers were in vehicles whose driver was aged 21 or younger, and 43% of the passengers were reported as not wearing seatbelts at the time of the accident.[38]

Figure 3.5: Youth (15–24 years) transport mortality rates per 100,000, by DHB of death, 2003–2007 combined
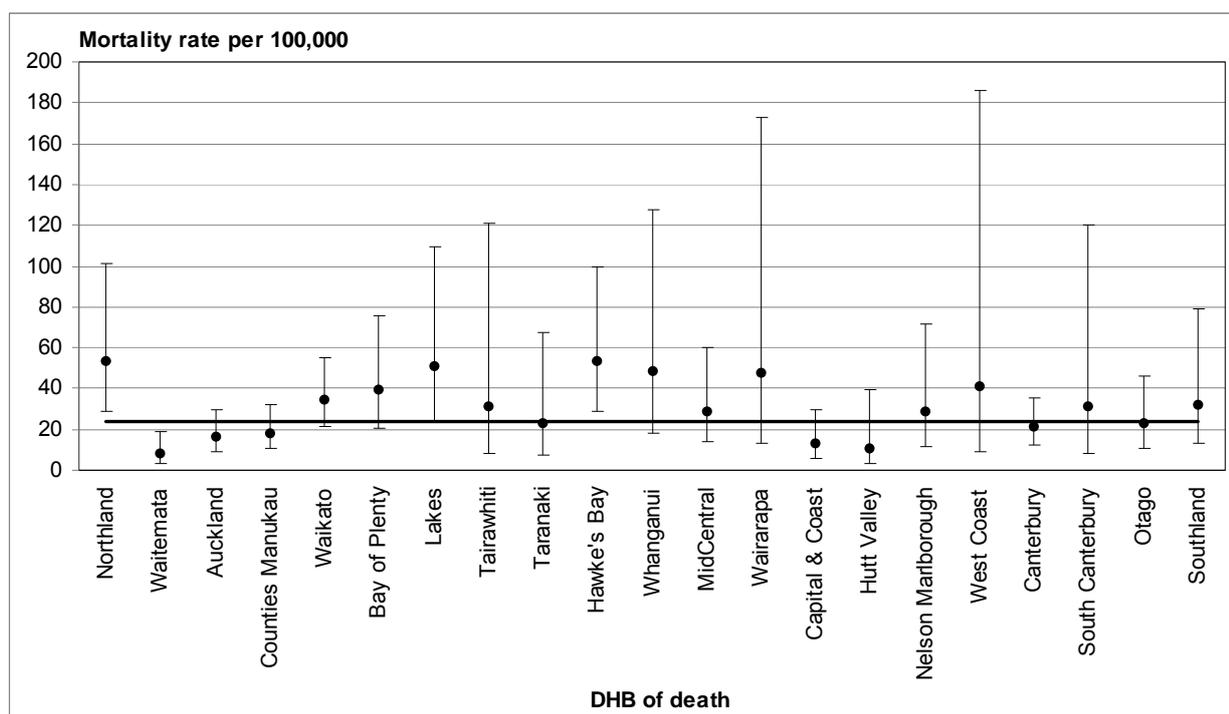
Notes: The line shows the national youth (15 to 24 years) transport mortality rate per 100,000 estimated residential population. The mortality rate by DHB of death uses the same denominator for each year; that is, the population by DHB according to the 2006 Census. No attempt has been made to estimate population by DHB for the years 2003–2005 and 2007. The exact method of Agresti and Coull has been used to estimate 95% confidence intervals.

Figure 3.5 shows that Northland and Hawkes Bay have rates of transport deaths that are significantly higher than the national rate. Waitemata is the only DHB with a rate significantly less that the national rate. While not significant for the individual DHBs, it is interesting to note that all the DHBs with lower than average death rates contain major metropolitan centres. These trends need further analysis to consider impact of public transport, lower speed limits and easier access to health care as being potentially protective, while rural roads with the associated increased distance driven at higher speeds may contribute to risk.

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[38] Note that use of seat-belts is not always able to be determined at the time of the accident.

Why are young people most at risk for motor vehicle fatalities?
by Dr Simon Denny, youth health physician at Kidz First Children's Hospital in Auckland

Driving is a dangerous activity for everyone, but it is particularly dangerous for young people. Young drivers (15 to 24 years old) are 3 to 4 times more likely to die in a motor vehicle crash than older drivers. Young male drivers are particularly at risk, with almost twice the number of young men dieing from motor vehicle crashes compared to young female drivers. Furthermore, newly licensed drivers (those in their first six months of driving) are about eight times more likely to be involved in fatal crashes than more experienced drivers (National Research Council et al 2007). In New Zealand, 62% of crash deaths among 15–19-year-olds are among drivers on their restricted or learner licence (Transport NZ 2008).

Lack of experience appears to be independent of the age of the driver. In other words, there is a learning curve for all new drivers. However, although driving becomes less risky with experience, young people are still more likely to underestimate dangerous situations than older drivers (Jonah and Dawson 1987). Other factors that potentially make driving dangerous for young people include driving at night, driving in the presence of peers, driving under the influence of alcohol and fatigue.

What do we know about New Zealand teenagers and their behaviours in motor vehicles?

A large national survey of New Zealand secondary school students in 2007 found that substantial numbers of young people take risks when driving or being driven in motor vehicles (Adolescent Health Research Group 2008a). Specifically:

- during the previous month, nearly one-quarter (24%) of students had been driven by someone driving dangerously

- during the previous month, 23% of students rode in a car that was driven by someone who had been drinking alcohol

- during the previous month, 10% of 17-year-olds had driven a car after they had drunk more than two glasses of alcohol in the two hours before driving

- more than one-quarter (26%) of students do not always wear a seatbelt when driving or being driven in a car.

3.4 Themes from the CYMRC database and local review process

During the period 2003–2008 a large number of cases involving the unintentional injury deaths of young people in New Zealand were considered by local child and youth mortality review groups.

The groups were often left with a feeling of frustration that many deaths from injury were preventable but it was unclear how and if the behaviour of young people could be changed. It seemed that existing injury control policies and programmes did not sufficiently address risk taking in young people.

On occasions, young people engaged in extremely risky behaviour and seemed completely incompetent at assessing the level of risk they were taking. At times, groups were left uncertain as to whether death was intentional or not. Few interventions seemed to focus on building "risk competence"[39] amongst young people. It was felt that young people need to learn to manage complex and hazardous situations and avoid harm and that this should be part of life skill acquisition. If such an approach was successful, alternative behaviours could develop for handling risky situations, to reduce the risk of injury. The sort of work is discussed below in the context of building resilience and has been attempted over seas (eg, European AdRisk 2008).

For the review of transport related deaths, information provided by police and the serious crash units was a very important part of these reviews. A number of themes and recommendations emerged from these reviews. Many of the drivers were young and inexperienced. The sudden transition that occurs with transition from restricted to full licence which allows driving alone or with peers, at night, and after consuming alcohol, appears a factor in a number of cases. Furthermore, training did not appear to equip young people with the skills required for difficult driving conditions. Common conditions associated with mortality were night driving, high speeds, and driving on rural roads, which are often gravel roads.

The reviews also suggested that drivers were often distracted: cell phone use while driving was a theme. Other common themes were not wearing seatbelts, unlicensed drivers, driving too fast, alcoholic intoxication, driving with peers, passengers consuming alcohol in vehicles while being driven, unlicensed and unwarranted vehicles and falling asleep at the wheel.

Alcohol is an important theme seen in many different types of death. A specific CYMRC report on the contribution of alcohol will be published in 2010. Recent New Zealand publications elsewhere highlight four key facts related to transport deaths in young people.

- Alcohol contributes to a higher proportion of fatal crashes in the 15–24 age group than in any other age group (Ministry of Transport 2009: 13).

- Alcohol has a greater effect on driving performance at lower levels for young people compared to older age groups (Ministry of Transport 2009: 16).

- Young drivers under 25 are less safe, considering fatal and serious injury, than they were a decade ago (Ministry of Transport 2009: 16).

- "The greatest risk period for young drivers is in the first six months of driving solo (ie, the first six months of gaining a restricted licence)" (Ministry of Transport 2009: 16).

In considering how to lessen the negative impact of alcohol on young people it is important to listen to the views of young people. In August this year, in the youth consultation on the *Safer Journeys* discussion document, 60% of young respondents supported the reduction of Blood Alcohol Content (BAC) for drivers under 20. Moreover, 68% supported the reduction of BAC for all adult drivers.[40] In the 2008 consultation on the National Alcohol Action Plan a majority of young people who took part in focus group discussions supported a zero Blood Alcohol Content level for all ages. In the last Youth Parliament in 2007, the Youth Transport Select Committee supported the reduction of the Blood Alcohol Content to zero for young drivers and for adult drivers. These are very wise comments in light of the fact that alcohol at all levels impairs driving competence (Ministry of Transport 2009: 13).

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[39] Risk competence is the capacity of individuals to recognise risk and dangers, to handle and cope with them, to make responsible decisions to avoid harm and to learn about and integrate challenges.

[40] Cited by Susan Wauchop, Ministry of Youth Development and Advisor to the CYMRC, in an email on 23 October 2009.

Case control studies in the United States comparing states that have moved to zero BAC for young people with states that have not, have shown a significant (22%) reduction in fatal crashes involving single vehicles at night. Where a lesser reduction in BAC was made, no significant reduction of fatalities occurred (Hingson R, Heeren T, Winter M, 1994). CYMRC supports zero BAC for young and/or novice drivers.[41] While there was concern that this might be seen as discrimination on the basis of age the committee believes the risks that cluster in this age group and while gaining driving skills justify such action. The community might also wish to consider having a zero BAC for all drivers of all ages in view of the harm caused.

In some cases it was clear that contact with health services had not resulted in the identification of risks. It was therefore suggested that risk assessment be routinely incorporated into youth health care practice as happens for family violence screening. To make a difference screening would need to be followed by interventions to reduce risk. In fact such risk screening is accepted as best practice and highlighted in the *Health and Disability Sector Standards (Child and Young People) Audit Workbook* (Standards New Zealand 2004).

Recent declines in motor vehicle crash deaths
by Dr Simon Denny, youth health physician at Kidz First Children's Hospital in Auckland

Over the past three decades motor vehicle crash deaths have been decreasing in New Zealand and internationally. Since the late 1980s the motor vehicle crash rate decreased from 20 deaths per 100,000 to approximately 10 deaths per 100,000 by 1995 (Ministry of Transport 2008). A similar reduction in motor vehicle crash deaths was observed for 15–24-year-olds over this time period. During the late 1980s approximately 300 young people (aged 15–24 years) died in motor vehicle accidents each year, which had halved to approximately 150 young people per year by 2000 (Ministry of Transport 2008).

This reduction in motor vehicle crash deaths is substantial. Although the exact causes for these reductions are unclear, the fact that the reductions were uniform across the population and were also seen in other OECD countries suggests that environmental improvements, rather than individual behaviours, contributed to these reductions. It is likely that the combination of safer cars, better roads and fewer alcohol-related crashes were significant. For young people, the graduated driving licence system introduced in 1987 may also have played a part, although this is somewhat controversial (Kingham et al 2008). Internationally, graduated licensing schemes are seen as an important initiative to reduce youth transport injury and death (Peden 2008).

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[41] The Committee hopes further collection of information from the CYMRC database will allow a more specific statement around definitions of young and novice.

Implications for policy

Although risk-taking during adolescence is normal, biologically driven and to some extent inevitable, there are several successful approaches to reducing risk-taking among young people or mitigating the effects of their risky behaviours. The first broad approach is to ensure the environments and settings that young people are growing up in are safer and healthier. A multi-pronged environmental approach would include policy changes, changes to the physical environment, improved access to social and health services, and community shifts in expected norms and behaviours. A reduction in motor vehicle crash rates will probably require approaches such as zero tolerance for alcohol when driving, changes to car design, re-engineering of dangerous roads, and measures to slow traffic. The focus of these approaches is not to change young people's behaviours directly, but to enable safer choices within a safer environment.

The second broad approach attempts to enhance the resiliency of individuals and the individual's propensity to engage in risky behaviours. Almost all the existing research on risk-taking by adolescents highlights the importance of caring and supportive parents in the lives of young people. Those young people who feel connected to their parents exhibit much lower levels of risk-taking behaviours in terms of sexual health, motor vehicle risk-taking, substance use and violence (Resnick et al 1997). Parents play an important role in the lives of teenagers, and they need to be aware of this.

Parents also need to be educated on the risks facing young people so that they can provide support and guidance. For example, parents need to understand the high-risk situations young people can encounter when they first start driving, such as driving at night, driving with peers, driving under the influence of alcohol and driving when fatigued. This is so parents can help teenagers identify these high-risk situations and monitor their behaviours to avoid potentially fatal motor vehicle crashes and reduce the number of young people dying from motor vehicle crashes on our roads.

3.5 Observations by the CYMRC on youth risk taking and injury

Mortality dramatically increases after age fourteen; risk taking behaviour is a major contributing factor. Risk taking substantially contributes to many different sorts of injury related deaths and high levels of non fatal injury. New Zealand has high levels of risky behaviour amongst youth people. It appears that existing injury control programs focus on specific policy areas, eg, transport, water, sport, workplace, school. Less effort is put into an approach that focuses on understanding the developmental context in which risk taking occurs. The fact that in Europe many similar countries have huge disparities in rates of unintentional injury death in young people suggests that risk factors may be modifiable through efforts at prevention (AdRisk 2008).

3.6 Recommendations by the CYMRC on preventing death by unintentional injury

Legislation

1. The allowable breath alcohol level for young and/or novice drivers should be lowered to zero.

2. Develop strategies to improve the safety of the environment. Such strategies might include the following:

   a. change regulations regarding access to alcohol

   b. change the Ministry of Transport regulations for licensing young drivers, introducing a system with more steps that better acknowledge the time taken to acquire the necessary skills

   c. encourage initiatives to reduce driver distraction and fatigue, such as the November 2009 ban on hand held cell phones

   d. review enforcement to ensure strategies used achieve increased safety.

Policy

3. Recognise injury as one of the most important health threats for young people and include it in the health policy agenda, including specific elements related to risk taking.[42]

4. Improve the collection and linkage of data about serious injury to allow better surveillance, analysis and reporting of the huge burden that injury imposes.

5. Youth health promotion, life skill programmes and injury prevention should include strategies to build risk competence and resilience that involve both young people and their parents.[43]

District Health Boards

6. Care pathways should be developed to support universal opportunistic psychosocial screening of young people which are linked to effective interventions to reduce risk if positive screening occurs.

Practice points

7. Health professionals should provide opportunistic psychosocial screening (as in the HEADSS assessment[44]) to all young people seen in health services. This includes screening for risky motor vehicle behaviours, especially in conjunction with alcohol use.

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[42] The European Commission has commissioned a series of documents that outline related issues. See http://www.eurosafe.eu.com/csi/eurosafe2006.nsf/wwwVwContent/l3launchofresults.htm?OpenDocument

[43] Parents of young people often need to be empowered to recognise their continuing role in parenting, which involves recognising risks and helping to modify behaviours.

[44] The HEADSS assessment is a tool that measures risk and resilience. HEADSS stands for a number of categories: Home, Education, Activities, Drugs & Alcohol, Sexuality, and Suicide.

8. Health professionals need to support parents and acknowledge the importance they play in the wellbeing of teenagers in their care. This includes educating parents on the hazards associated with learning to drive and using motor vehicles.

9. Health professionals need to help others to understand the development of young people and work with communities to create opportunities that build risk competence and resilience especially for young men.

Community messages

- Young people are supported by, and connected best with, services when leadership results in services that connect to each other, collaborate and are cohesive.

- It is inevitable that young people will take risks, it is a part of normal development. Communities need to ensure that learning opportunities and stimulating environments are available where young people can explore and develop their physical, psychological and social skills without undue risk of injury.

- Environments where young people take risks and try out new experiences need to be as safe as possible and not isolated from all adult support and supervision.

- Schools, sporting groups and communities need to recognise the harm that alcohol contributes to the lives of young people, ensure appropriate role modelling, and make events and activities safe with alternatives to alcohol abuse and misuse being available.

- Parents need to understand their changing role as their children grow into young people. At this time the challenges of parenting become different, but that does not mean parenting becomes less important. Parents should strive to remain connected and support their young people in risk recognition and safe decision-making.

- Parents also need to be educated on the risks adolescents face when beginning to drive, especially in high-risk situations such as driving with friends, driving at night and driving under the influence of alcohol.

- Parents need to recognise that friends are extremely important for young people's healthy development, but young people still need their parents' support and guidance as they navigate potentially unsafe situations that are exacerbated when they are with their friends.

4   Youth Suicide

4.1   Introduction: death from intentional self-harm

International comparisons show that New Zealand has the highest rates of youth suicide in the OECD for both men and women aged between 15–19 years according to a recent OECD publication(OECD 2009a). Caution needs to be taken when making international comparisons of suicide rates because many factors affect the recording and classification of suicide and can result in undercounting of suicide in other countries.[45] However, it is a significant concern that too many young people die by suicide in New Zealand.

Figure 4.1:   Youth suicides per 100,000 youth aged 15–19 years in the OECD, by sex (data averaged for the most recent three years)
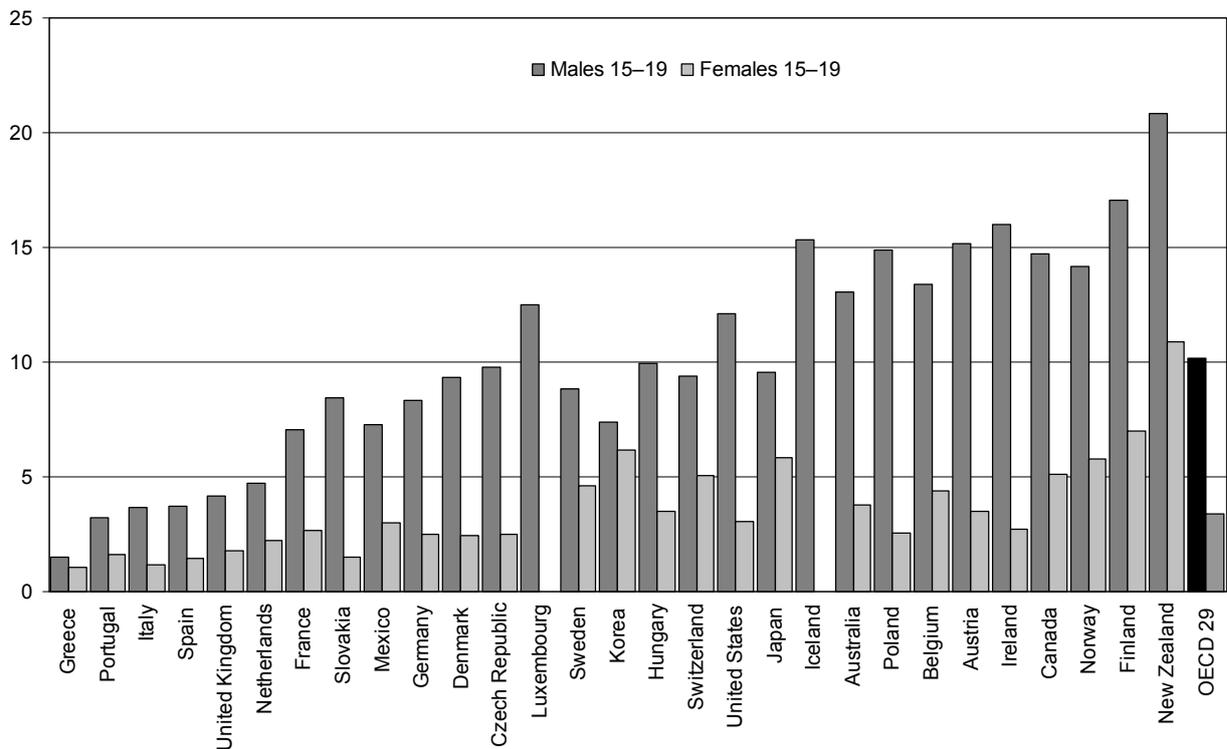
Source: *World Health Organization Mortality Database 2008*, as cited in OECD 2009a: 52.

Notes: Comparability of suicide statistics is dependent on reporting mechanisms in each country, as varying degrees of social stigma associated with suicide may lead to variations in under-reporting. No data is available for Turkey. There were no reported female youth suicides in Luxembourg and Iceland during the period.

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[45]   Key factors influencing reporting rates are the level of proof that is required for classification of a suicide, which is very thorough in New Zealand and is made after a coroner's investigation. This means compared to other countries New Zealand has a low number of "undetermined deaths." The stigma associated with suicide may also influence reporting rates as it deters the classification of a death as a suicide in some countries.

In the early 1900s the highest rates of suicide in New Zealand were in the over 45 year age group. Since the mid-1980s this trend has changed, with the highest rates being in the under 45 years age group, and the highest rates across all ages being in the 15–24 years age group (Ministry of Health 2008a: 4). The rate of suicide in this age group (ie, 15–24-year-olds) increased from 15.6 per 100,000 in 1986 to a peak of 28.7 per 100,000 in 1995 (Ministry of Health 2008b: 6). The rate then decreased until 2000, where it appears to have reached a plateau at an average of 17.8 per 100,000 over the past five years, according to CYMRC data.[46] This rate is still higher than in the early 1980s, and is significantly higher than that recorded during the 1940s to 1960s of less than 5 per 100,000.

Every year approximately 110 young New Zealanders (aged 10–24 years) die by suicide.[47] This accounts for about a fifth of the total number of suicides each year in New Zealand.[48] The development of effective population-based strategies for suicide prevention is dependent on a clear understanding of the risk and protective factors relevant to New Zealand youth, along with ongoing information about the rates and causes of suicidal behaviour.

4.2 Statistics on youth suicide from the CYMRC database and other sources

Suicide now accounts for about 25% of the deaths of young people aged 10–24 years (see Table F.1, Table G.1, and Table H.1 in the appendices.) Approximately 75% of these are males and 25% are females.

Table 4.1: Suicide deaths (numbers and age-specific rates per 100,000), by age group, 2003–2007[49]

Age group	Gender	Deaths						
		2003	**2004**	**2005**	**2006**	**2007**	**Total**	**Average rate**
10–24 years	Female	33	37	24	28	26	148	6.6
	Male	71	85	86	100	70	413	17.9
	Total	104	122	110	128	96	561	12.4
15–24 years	Female	32	32	24	23	25	137	9.3
	Male	66	80	83	99	68	396	26.4
	Total	98	112	107	122	93	533	17.9

Māori young people have a disproportionate rate of death due to suicide compared to their non-Māori counterparts. The rates of suicide in Māori aged 15–24 are over two times that of non-Māori in the same age group. Although the rates of suicide in Māori and non-Māori have decreased from a peak in 1996, this decrease has been substantially less in Māori. The rate of suicide in Māori has decreased by 14% since the peak in the late 1990s, and

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[46] This average rate was calculated using data from Table 4.1 and data from the CYMRC's *Fourth Report to the Minister of Health*. The 2008 data included in Appendices G and H is not considered here as too many cases were awaiting coroners when the data extract occurred. Appendices G and H can be found online at http://www.cymrc.health.govt.nz, *Fifth Report to the Minister of Health: Reporting mortality 2002–2008.*

[47] This average was calculated using data from Table 4.1.

[48] 'Each year approximately 500 New Zealanders die by suicide' (Ministry of Health 2008b: iii).

[49] The CYMRC suicide data on the number of suicides per year differ from that published in the Ministry of Health Suicide Facts series. This is primarily because the Ministry of Health reports by year of registration of death whereas the CYMRC reports by calendar year of death. It will also differ because the number awaiting coroner reports changes over time and local review groups may amend the cause of death before it is reported by the coroner.

during this same period the rate in non-Māori has decreased by 21% (Ministry of Health 2008a: 5).

Figure 4.2: Suicide deaths (age-specific rates per 100,000), by ethnicity and age group, 2003–2007 combined
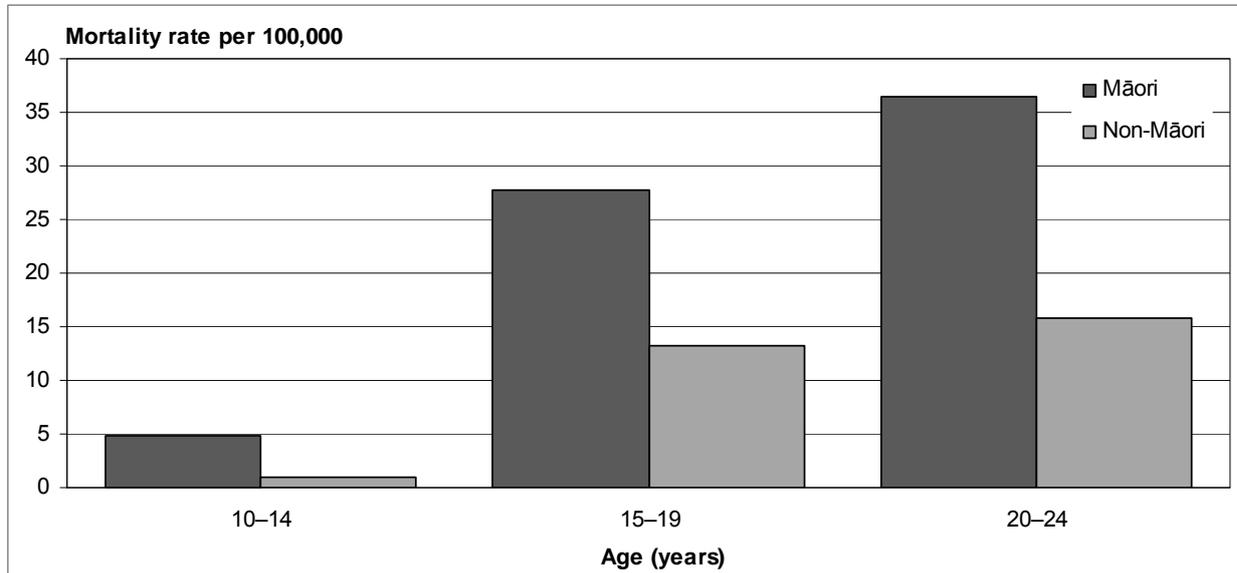
Risk factors for suicide have been shown to include mental health disorders including depression, non-heterosexual attractions, adverse experiences, including sexual, physical and emotional abuse, neglect, family breakdown, family violence, parental mental illness, alcohol and drug abuse, and having a friend or family member attempt suicide.[50]

4.2.1 The National Survey of the Health and Wellbeing of New Zealand Secondary School Students

An understanding of emotional health is very important to understand New Zealand suicide rates. The CYMRC data alone is unable to provide such detail, but the findings from the Adolescent Health Research Group complement the CYMRC data in this regard. This group, at the University of Auckland, has conducted two national surveys (one in 2001 and a second in 2007) of New Zealand secondary school students. These surveys provide valuable information on the emotional health of New Zealand youth.

Issues of mental health and wellbeing are a concern for many New Zealand youth, particularly females. Emotional health concerns such as depression dramatically increase around puberty, and significant numbers of young people, especially females, have high rates of depressive symptoms (Adolescent Health Research Group 2008a: 24). Twenty-seven percent of young people attending high school in New Zealand in 2007 reported being depressed for two weeks or more in the past 12 months; 20% of them had deliberately self-harmed in the last 12 months; and about 15% of those who deliberately harmed themselves required treatment by a doctor or nurse (Ibid: 102).

While the majority of young people indicated they had good emotional wellbeing, with 86% reporting some sense of satisfaction with their life, almost 15% of females and 7% of males reported levels of depressive symptoms that are considered to be serious and in need of professional assistance. In addition, 14% of the young people surveyed (19% of females

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[50]   See Ministry of Health 2008a for more details on risk factors associated with suicide.

and 9% of males) reported that they had serious thoughts of suicide in the past 12 months, 8.6% had made a suicide plan and 4.7% (7% of females and 3% of males) reported having attempted suicide (Adolescent Health Research Group 2008a: 24; Adolescent Health Research Group 2008b: 103). About 25% of these attempts were significant enough to have required treatment by a doctor or nurse (Adolescent Health Research Group 2008b: 103). While these numbers are still too high, the data from 2007 does show "a marked improvement in students' emotional wellbeing and associated behaviours" compared to the 2001 findings (Adolescent Health Research Group 2008a: 25).

Young people rated emotional worries as one of the health issues they had the most difficulty getting help with, second only to getting help for an injury or accident (Adolescent Health Research Group 2008b: 93). Nine percent had difficulty getting help for an emotional worry (Ibid). Reasons for not accessing health care included not wanting to make a fuss, not being bothered, being too scared, concerns about confidentiality, cost, not being able to get an appointment, lack of transportation, not feeling comfortable with the person, and not knowing how to get help or contact the health professional (Adolescent Health Research Group 2008b: 92–93).

Young people are the least likely of any age group to visit a health service for mental health concerns. This is despite their high levels of mental health needs. Young people are more likely to access health services if they are youth friendly and targeted to their needs (eg, school-based or 'one-stop-shop' health centres).

Violence is closely associated with suicide attempts in young people. Factors associated with suicide attempts in young people were witnessing family violence against adults, being the perpetrator of any serious violence, unwanted sexual contact, frequent bullying and frequent physical violence (Fleming et al 2007).

A cluster of adolescent deaths from self-harm in 2006: report of a local child and youth mortality review group investigation
by Barry Taylor

Introduction

During six months in 2006 there were six deaths by suicide of adolescents aged 15–18 years in an area of New Zealand where normally there would only be one death every two years. After reviewing various definitions of clustering we were able to find this constituted a cluster.

This cluster of adolescent suicides was not recognised as such until after the fifth death, when the possibility of a contagion effect was raised. The CYMRC process enabled an intersectoral multidisciplinary review to occur, and this report summarises the main findings and recommendations.

Figure 4.3: Deaths from intentional self-harm, 15–18-year-olds, cluster DHB and four comparison DHBs, 2002–2008
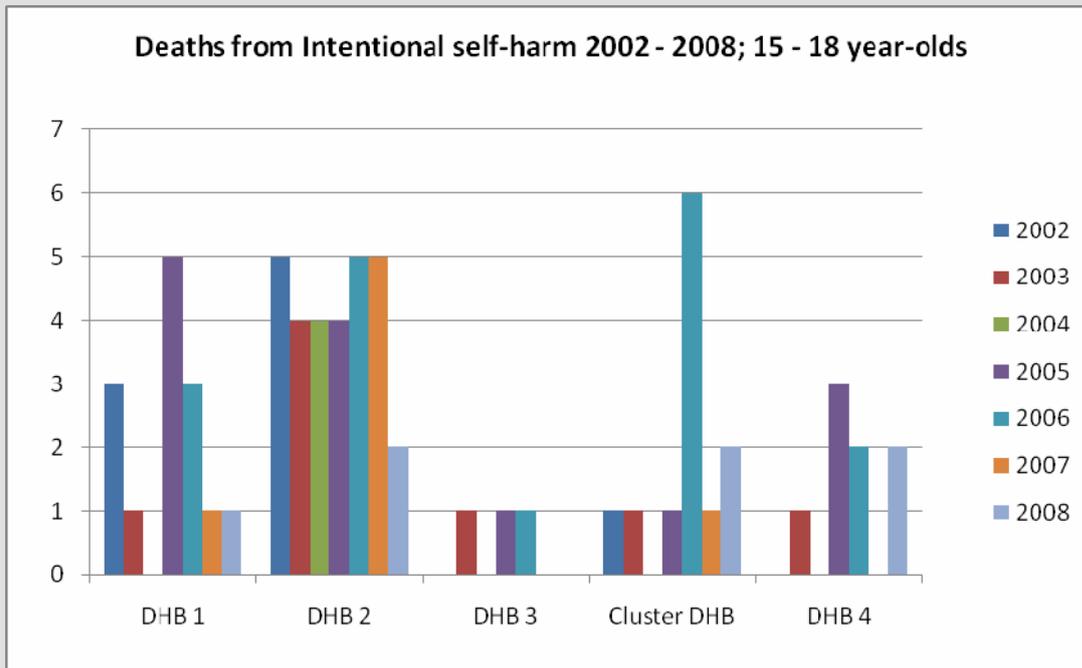
The review of the cluster consisted of three integrated processes.

1.   Review of cases

The initial focus was to examine the events surrounding the identified cases.

The agreed case definition was 'a person aged 15 to 18 years living in the cluster DHB who died from self-inflicted injuries between 1 June 2006 and May 2007.

A survey instrument was developed to systematically collate information on each case. The focus was on describing the characteristics of the cases, identifying any risk factors and precipitating events, and considering whether contagion had occurred, as well as highlighting any systems issues of concern.

Sources of information were:

- health records from hospital psychiatric services, GPs and any involved community agencies
- school records from school counsellors
- public health nurses
- police information from forensic examination of computers and cell phones
- interviews with family members who wished to talk to the review team.[51]

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[51] The mortality review group does not usually contact the families of cases it reviews, although parents and whānau do have an opportunity to provide comment related to the events surrounding the deaths of loved ones by accessing the national CYMRC website (http://www.cymrc.health.govt.nz/). The investigation group decided that the chair of the group (a paediatrician with experience in talking to families after the death of their child) and co-ordinator should make contact with appropriate family members of the cases to request a further interview based on key questions developed by the review team. A letter was sent to the families explaining the purpose of the request for a meeting, along with assurances that any information gathered would remain confidential and anonymous if used in any report. A follow-up letter and phone call were made to those families who had not responded within two weeks. Three families agreed to an interview.

2. Review of non-fatal suicide attempts presenting to emergency departments

To ascertain if there had been any increase in non-fatal self-harm admissions contiguous with the cluster a paper review was made of a random selection of these admissions. No increase in admissions for self-harm was seen, and there appeared to be timely and appropriate assessment by the emergency mental health services.

3. Review of interface between school counsellors and health services

A meeting with all local school counsellors was held to discuss school counsellor involvement with suicidal youth and access to mental health services.

Main findings

- The funeral for the index case was large and attended by a large proportion of the involved school.

- There were contacts or connections between at least four of the cases – probably mainly through the informal social networks.

- Knowledge of the suicide cases spread rapidly among the youth of the region and subsequently to parents. The use of texting appears to be important in this rapid spread of information.

- There was considerable misinformation spread by these means, both about the number of cases and about the possibility of a 'suicide pact' among young people in the region.

- There were clearly identifiable predisposing factors and precipitating events (usually relationship break-up) in most of the cases.

- Most were not involved with primary or secondary mental health services. For those who were, some difficulties were identified relating to appropriate 'engagement' and co-ordination of care over long time periods.

- For many of the cases there was extensive use of the internet and cell phone texting. Text and internet bullying does occur, but a case series such as this does not allow us to determine if this is a significant risk factor.

- There are considerable improvements possible in how the DHB monitors the mental health of youth, how it identifies youth mental health issues, and how it connects individuals requiring mental health support to appropriate well-trained services.

- A number of issues related to school counsellors arose:
  – Schools are not *required* to employ any school counsellors.
  – There are no national or local recommendations for what is the appropriate school counsellor to pupil ratio.
  – There is a gap in training among some school counsellors relating to crisis intervention after non-fatal and fatal suicides.
  – School counsellors are not required by the schools to have any formal training or registration with a professional counselling body. This may be due in part to a lack of understanding by the school of counselling and the counsellor's role in the school. In the DHB concerned, about 70% do have training, or registration with an appropriate body.

- School counselling is a difficult and taxing occupation. School counsellors need to have their practice under regular review by a process of formal supervision. This supervision should be with a professional with recognised expertise in the mental health area.
- A formal consultation with local youth suggests that most would find it difficult to approach and confide in school counsellors because they are seen as one of the 'teaching' staff. The dual roles of teaching and pastoral care may therefore act as a barrier to access.

- The DHB emergency services appropriately deal with acute self-harm events and are attended to immediately by the emergency psychiatric service.

- On referral to specialist secondary care, mental health services engagement can be slow (51% seen by the service more than 7 days after presentation). This strongly limits the ability of the service to engage the client. Also, specialist secondary care mental health services connection and liaison with schools has not been a priority and has therefore been erratic. The perception from the school level is of difficulty getting adequate and quick responses when they are needed from the specialist secondary care mental health services.

- There is a gap in the availability of counselling services for those youths who fall outside the moderate to severe category of mental health.

- Support for the family and friends of those who die from suicide is limited in the cluster DHB.

4.3 Recommendations from the CYMRC local review process

A review of the recommendations made by the local child and youth mortality review groups regarding death by suicide shows a number of common themes.

- **Access to health services.** Access to health services is one of the most common themes that has emerged from the local child and youth mortality group reviews of death by suicide. For some young people this means difficulty accessing needed services. Some reviews showed that there appears to be a lack of youth-friendly services related to mental health and/or drug and alcohol addiction.

  Not all youth mental health services maintain a supportive relationship with school counsellors. Supporting school counsellors could be identified in the job description of specific staff to make sure school counsellors have access to resources to help them cope with the mental health needs of students. Current systems can have waiting times that make appropriate engagement at the right time difficult, and so the DHB could consider establishing mechanisms for meeting this need (eg, funding private sector counsellors or psychologists for this work, or possibly using the model used by the Family Court referral scheme for relationship and parenting issues). This would provide early intervention for moderate-needs youth.

  There were instances of referral but no follow-up when the young person did not attend appointments. This indicates a different kind of problem. Health care providers must have checks and balances in place to prevent patients – particularly patients who are at high risk of self-harm – from falling through the cracks in the system. (See Chapter 5 on System Improvements.)

  At times families and friends recognised the distress a young person was suffering but were unsure where to seek help or were unable to persuade the young person to engage

help before suicide was completed. It seemed primary health care was not viewed as the obvious place to seek help for emotional distress or depression.

- **Staff skills and practice.** Not all health professionals are adequately skilled to provide assistance to young people. Health care providers need additional skills in understanding confidentiality issues both from the point of view of when to preserve confidentiality and when they are obliged to share information. (See Chapter 5 on System Improvements.) Full psycho-social health assessments such as the HEADSS assessment done by appropriately skilled staff do not always occur. They should be universally performed by staff skilled in their use, as screening and detection tools in much the same way as family violence screening occurs.

- **Multiple service providers.** Another common theme identified in the local reviews was the sharing of information between multiple service providers. While many of the reviews showed that the youth had a history of service provision, sometimes information was not being shared between providers.

  In at least one DHB region the local mortality review of youth suicides has directly resulted in system changes in protocols between police and mental health services to support collaboration and enhance the potential to prevent further deaths.

- **Bereavement.** The reviews also showed that youth who have experienced the death of a loved one (often via suicide as well) are at a greater risk for self-harm. For this reason, the development of after-death care pathways are important. (See Chapter 5 on System Improvements.) The Ministry of Education post traumatic incident support was seen by local groups as very helpful and supportive. Not all schools choose to use this service. Schools often need support around managing involvement in funeral care and organisation so as to minimise distress and the potential to promote suicide contagion. The media has an important role with regard to the responsible reporting of suicide. Media guidelines have been developed to reduce the potential for future copycat suicides (Ministry of Health 2008a: 48).

- **Building resiliency.** Childhood and adolescence are times when the development of positive coping strategies and increased self-esteem can lead to increased resilience despite adverse events. Protective factors include warm and caring families, and safe schools and communities. (Simon Denny argues the same point in Chapter 3.) Youth mentor programmes can be very effective in building resiliency for young people. Research shows that young people are more resilient when they have healthy connections with family, school, culture and community as well as a sense of purpose.

4.3.1 Suicide prevention in New Zealand

In 1998, the *New Zealand Youth Suicide Prevention Strategy* ('In Our Hands' and 'Kia Piki te Ora o te Taitamariki') was launched as a result of collaborative work across three Ministries (Ministry of Youth Affairs et al). The five goals it contained remain valid today and are echoed in the issues raised in the cluster review and from the CYMRC local reviews. They are also relevant to youth support in general and reducing the toll from risky behaviours highlighted in Chapter 3 of this report.

1. **Promoting Wellbeing** – To prevent young people becoming at risk of suicide through strengthening families and whānau, young people and communities.

2. **Early Identification and Help** – To better identify and help young people at risk of suicide, and reduce opportunities which present suicide as an option.

3. **Crisis Support and Treatment** – To improve support and treatment for young people who have attempted suicide or who are suicidal.

4. **Support After Suicide** – To give effective support to those who are bereaved or affected by a suicide, and to reduce the potential for further suicides.

5. **Information and Research** – To improve information about the rates and causes of suicidal behaviour in young people to inform effective prevention efforts.

In 2006, the focus on suicide prevention in New Zealand changed to one to involve all ages with the publication of the *New Zealand Suicide Prevention Strategy 2006–2016* because almost 80% of suicides occur over the age of 25. With development of this all-ages approach it is important that the specific needs of young people are not forgotten. The vision and inspiration for the strategy is:

a society where all people feel they:
- are valued and nurtured
- value their own life
- are supported and strengthened if they experience difficulties
- do not want to take their lives or harm themselves.

It is very easy to appreciate that the needs of young people in these regards will be very different from the needs of others.

To achieve the above vision, the Strategy sets out broad areas for action, described as seven goals. Covering the spectrum of prevention and setting the directions for New Zealand's efforts for the next 10 years, the seven goals are as follows:

1. Promote mental health and wellbeing, and prevent mental health problems.

2. Improve the care of people who are experiencing mental disorders associated with suicidal behaviour.

3. Improve the care of people who make non-fatal suicide attempts.

4. Reduce access to the means of suicide.

5. Promote the safe reporting and portrayal of suicidal behaviour in the media.

6. Support families/whānau, friends and others affected by a suicide or suicide attempt.

7. Expand the evidence about rates, causes and effective interventions.

These documents have provided a valuable focus on prevention and the Ministry of Health continues to lead a multi-sectoral approach to suicide prevention. As new work, such as the primary mental health initiative, is developed, it is very important the needs of young people continue to be considered.

The local child and youth mortality review groups have been asked to use the seven goals as a framework to highlight what preventive interventions might have averted each completed suicide.

Five DHBs are currently running pilot studies with local suicide prevention co-ordinators. Some of these co-ordinators are also members of local child and youth mortality review groups. This is a particularly valuable link because these individuals can gain access to information to inform their work and their specific role allows them to convert the learning from local review into practice.

4.4 Recommendations by the CYMRC on suicide prevention

4.4.1 Policy

1. The CYMRC supports, as a high priority, specific preventive work in every DHB with central leadership to achieve the seven goals of the *New Zealand Suicide Prevention Strategy*.

2. The youth-focused actions suggested from *In Our Hands* should be remembered and youth specific elements should continue to be formulated within the current suicide prevention initiatives.

   - Health services geared towards, and accessible to, young people (eg, youth one-stop shops and school health clinics).

   - Endorsement of worldwide youth health standards, similar to those promoted by the Society of Youth Health Professionals Aotearoa New Zealand (SYHPANZ).[52]

   - Greater intersectoral collaboration, working across primary and secondary care, school services and mental health services, including drug and alcohol.

   - Support research about the nature, correlates and causes of suicidal behaviours, and research into resiliency.

3. The impact of modern communications technologies on adolescent suicide should be acknowledged and better understood.

   - The Ministry of Health review of its guideline *Suicide and the Media* should include advice around modern technologies.

   - Health research funding bodies should consider funding research to identify if and how modern technologies contribute to suicidal predisposition, precipitation and completion.

4. The Ministries of Health and Education should jointly review the role of school counsellors. This review should consider: whether the role is educational guidance counsellors or health/social services counsellors; staffing levels; training requirements; professional development; and how they might be better supported by the health sector. School counsellors should:
   - have appropriate skills
   - be registered with a professional association
   - be integrated into the whole of the school
   - have regular supervision from someone with appropriate skills
   - have a supportive relationship with mental health workers.

5. Appropriate procedures and use of Ministry of Education post traumatic incident support by schools should be included within the elements of school performance reviewed by the Education Review Office.

6. The Ministry of Health should monitor and respond to performance of primary health organisations (PHOs) with regard to coverage of service and capitation for care in young people.

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[52] For more information see http://www.nzaahd.org.nz/index.php/youth-health/youth-health-professionals

4.4.2 District Health Boards

7.   Each DHB should have in place:

- a suicide prevention action plan to implement the *New Zealand Suicide Prevention Strategy 2006–2016*, with a focus on youth

- a mechanism for identifying community-based health crises, including those relating to mental health and suicidality, which links to a multidisciplinary response with clearly assigned responsibilities

- a mechanism for supporting families bereaved by suicide

- a system that uses what is learnt from cases of suicide to modify local systems of care, prevention and support

- an assigned role for specific staff to maintain a strong supportive relationship between youth mental health services and school counsellors

- a system whereby referrals from school counsellors receive timely care

- a system that ensures all mental health concerns are taken seriously

- PHOs need to make efforts to improve coverage of care for young people and use strategies such as youth one-stop shops and school based clinics to enable increased coverage.

Community messages

- In communities where leadership across sectors results in services that are connected, collaborative and cohesive, it is easier for young people to obtain support and connect to the services they need.

- Developmentally young people can be vulnerable and we need to be vigilant to changes in mood, presentation and actions.

- Emotional and mental health problems can be serious and require professional attention. General practice or youth health clinics are appropriate places to seek help.

- When a young person has been identified who needs mental health services, there are a number of youth-specific resources available, such as Youthline, Mental Health Line and What's Up.

- Spend time with young people to build connections, give a sense of purpose and enhance resiliency.

- Strengthen the whānau, social networks and community networks around young people. Disengaged young people are at particular risk.

- Value young people, focus on their strengths and support them in finding purpose.

- Involve young people in decision-making.

5   Systems Improvement

5.1   Introduction

The data collected by the local child and youth mortality review groups since 2002 shows that the need for systems improvement within health and other sectors is a common factor that cuts across all causes of death. Appropriate recommendations for systems are difficult to develop because the layers of contributing factors are often incredibly complex. However, the CYMRC recognises that systems issues must be tackled, despite the complexity and challenges associated with initiating change.

This is the first CYMRC annual report to include a section devoted entirely to systems improvement. The CYMRC expects to continue presenting this section in future reports because systems improvement is fundamental to the prevention of deaths across all of the Mortality Review Committees. The evidence for this section is based on the qualitative narratives that accompany each local death review. The resulting recommendations from local reviews were systematically analysed in order to identify common themes associated with system improvement.

This chapter does not seek to assign blame to any individuals or organisations. Rather, the focus is on how systems can be improved so that children and young people in New Zealand receive the best care possible.

Kohn et al define a system as 'a set of interdependent elements interacting to achieve a common aim. The elements may be both human and non-human' (2000: 52). Non-human elements include equipment and technologies developed to support a system. This definition is useful for our purposes because it suggests there are many actors in a system, so the responsibility to address any potential failures in a system must be shared by all of the actors involved. In some cases it was clear that problems arose because a well-connected system did not exist.

5.1.1 Improving the mortality review system

Over the last seven years much of the work of CYMRC has focused on setting up a system for mortality review[53] that will collect data and process it into information that highlights how, where and why risks of death cluster.

If the information gained from mortality review is to make a difference, it needs to influence other systems that work at individual, community and national levels. Mortality review can be a valuable tool for continuous quality improvement, supporting others to better assess risks and deliver interventions that reduce risk.

CYMRC has work planned to develop methods of analysis that make it easier to look at themes that contribute to death from many different causes (eg, alcohol may contribute to death from transport injury, assault and drowning). The Committee is continuing to build the national network of local child and youth mortality review groups (LCYMRGs) and develop better arrangements to work with advisors and researchers, all of which are systems that increase the influence of, and the value gained from, the process.

While accurate, routinely-collected mortality data is presented in this report, similar data reflecting the burden of morbidity from injury is not routinely available. At times the

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[53] The CYMRC Mortality Review Process is described in Appendices A and B (available at www.cymrc.health.govt.nz).

mortality data might indicate a small number of deaths, but neglects to show that a major burden of (potentially avoidable) morbidity occurred as well.

Figure 3 The injury 'iceberg'

For every one death among children aged 0 to 14 in the Netherlands during 1991-95 (home and leisure accidents) there were:

- 160 hospital admissions
- 2,000 accident and emergency department visits
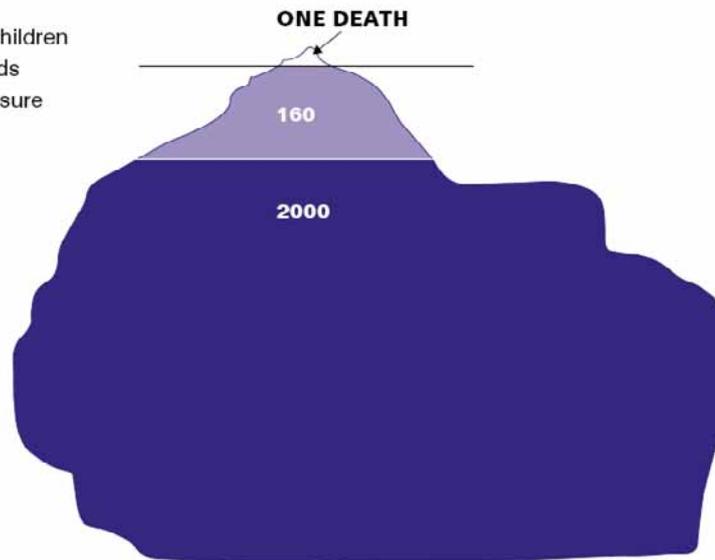
Source: UNICEF Innocenti Research Centre 2001.

Each condition has a different "Pyramid of Injury" (Trotter, Russell, Langley, and Casey 2005) that describes the burden of morbidity associated with each death. In Chapters 3 and 5, the lack of information about morbidity, particularly the frequency of permanent disability injury, was highlighted. Ideally, injury severity scoring information should be available; currently no ACC or health system routinely publishes this information. Such scores are vital to help plan injury prevention priorities. Without these scores priorities may be distorted because the main sources of information counted are deaths, hospital costs and case numbers which may have little bearing on morbidity or severity of injury. In the future it would be hoped that a national injury system could be informed by both mortality and morbidity data and such information become routinely available.[54]

It is therefore recommended that New Zealand develop better injury systems that link and collect data, perform surveillance, and report. Such systems can support the development of effective injury prevention and safety promotion by providing a basis for the formation, implementation and evaluation of evidence-based injury prevention strategies (MacKay et al 2006; European AdRisk 2007; National Trauma Registry Consortium (Australia and New Zealand) 2008). It is important that the special requirements of infants, children and young people are not lost within a system designed for adults. The cost of single cases of traumatic brain injury in childhood can be extremely high, up to $20,000,000.[55] Small changes in case numbers can therefore have major implications.

Local review groups have identified some types of deaths where the responsibility for implementing system improvements lies with different government agencies depending on where the death occurs. This is not to suggest it is not clear who was at fault; rather, it means that it is not clear who should take responsibility and a leadership role in creating improvements. Types of death that stand out in this regard are driveway deaths,[56] farm

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[54] The NZ Injury Prevention Secretariat and Statistics NZ are currently funding the Injury Prevention Research Unit at the University of Otago to develop a robust injury disability indicator that is informed by both mortality and morbidity data.

[55] Jan White, ACC CEO, in speech to Health Select Committee on 19/8/2009.

[56] "Driveway deaths" also occur in private and public car parks, garage forecourts and at the junction of driveways and roads, impacting on which agency reviews the case.

transport deaths and off road recreational vehicle deaths. New Zealand has the highest reported number of driveway deaths in the world (Beasley 2009). New Zealand also has a very high rate of farm transport deaths in relation to other countries.

Deaths related to roads are reviewed by the Ministry of Transport. Workplace-related deaths are reviewed by the Department of Labour. Recreational off road vehicle deaths get various reviews but may not fall to any one lead organisation. One organisation, ACC, is liable for the costs that arise from deaths or injury in any of these settings. So children and young people on farms, off-road in all terrain vehicles or in driveways may die with no organisation maintaining a systematic overview of the whole picture for this class of death. A systems-focused, collective strategy to reduce these types of deaths has the potential to make a difference, but this requires organisational leadership.

Implementing change

Systems that deliver health, education and welfare are complex with some elements of care being for everyone (ie, universal) while other parts are targeted. Interventions to reduce risk can occur at many levels. Simply telling people to do things differently has limited benefit. The *Child Safety Good Practice Guide* (MacKay et al 2006) highlights a variety of interventions that can be used to complement each other.

1.	Environmental modification (eg, pool fences, car seats, and road designs).

2.	Product modification (eg, air bags in cars, hands free cell phones, blister pack medication, and safe hot water temperatures).

3.	Legislation, regulation and enforcement (eg, legal limits for alcohol while driving and cycle helmet laws).

4.	Promoting the use of safety devices (eg, smoke detectors and car seats).

5.	Supportive home visits to families of young children (eg, Whānau Ora, Plunket, and Family Start).

6.	Community-based interventions (eg, cost adjustment and mentoring programmes).

7.	Education and skills development (eg, media work, motivation and support).

5.1.2 Improving care from health and social services

A significant proportion of the recommendations recorded in the Mortality Review Database relate to two main age groups: birth to five years and adolescence. For birth to five years the emerging themes showed that the quality improvement focus needs to be on strengthening communication and information sharing between all providers in the infant and maternal care continuum.

For late adolescence there is an identified need to create more efficient transitions from child and youth to adult services, better mental health services, a strengthening of communication between general and specialist providers, and a strengthening of communication between health services, social services and the education system.

The themes for birth to five years and late adolescence run parallel with the profile of the two peaks in deaths that occur across the child and youth age span of 28 days to 24 years, as shown in Figure 5.1. Strategies that seek to reduce deaths in these age groups will also reduce rates of morbidity and serious injury causing lifelong impairment.

Figure 5.1: Total number of deaths, by age, 2002–2008 combined

Number of deaths

A bar chart showing the number of deaths by age (years) from 0 to 24:

Age	Deaths
0	900
1	233
2	102
3	76
4	71
5	57
6	50
7	57
8	44
9	60
10	41
11	49
12	71
13	86
14	109
15	170
16	254
17	296
18	343
19	291
20	313
21	268
22	294
23	262
24	230

Age (years)
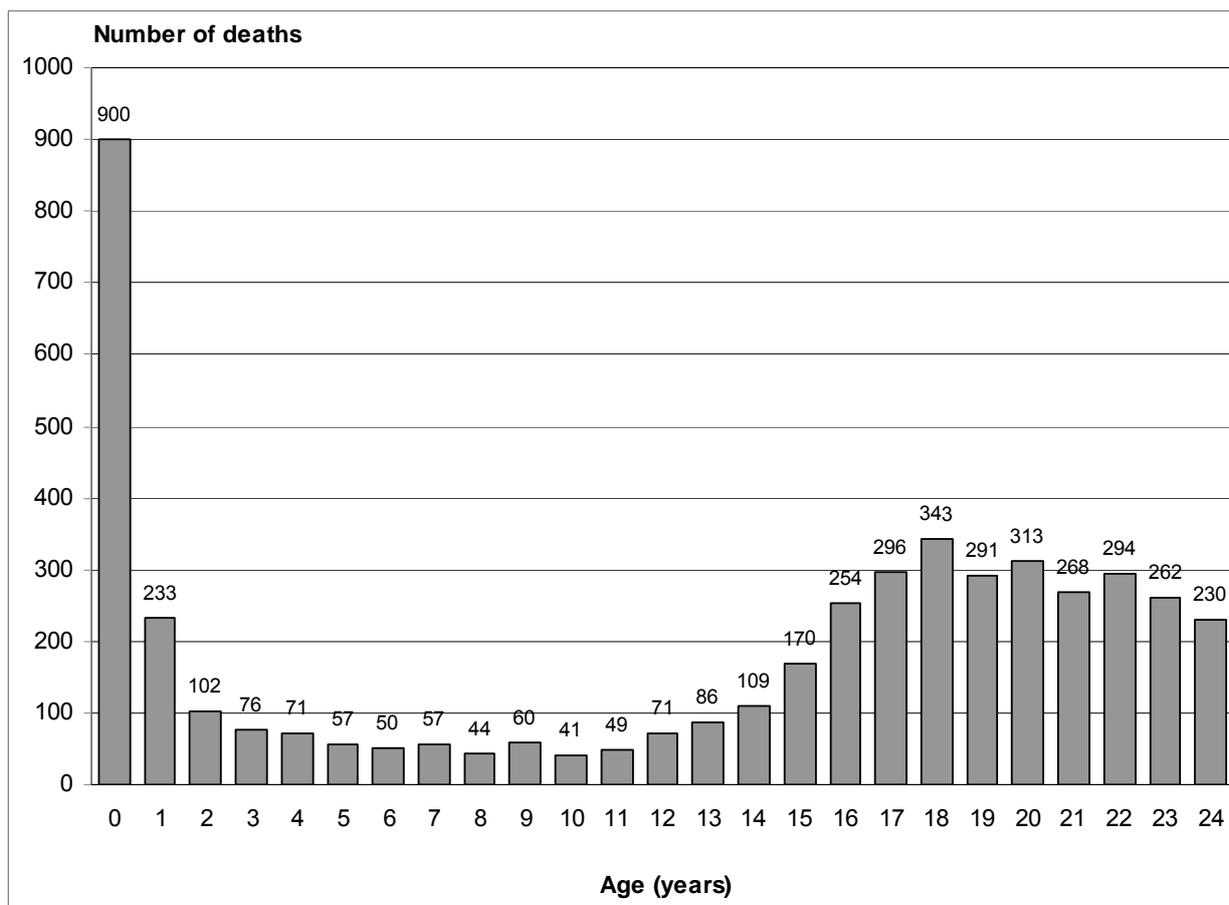
Note: The deaths in the 0 age group do not include any deaths in the first 28 days of life. Deaths in the first 28 days of life are reported by the Perinatal and Maternal Mortality Review Committee (PMMRC).

In both these age groups there is huge potential for quality improvement that strengthens the links between disciplines, organisations and sectors to reduce mortality and morbidity. Good links require an awareness of other services, an understanding of mutual needs and a commitment to continuous development and monitoring.

It is vital that appropriate life-saving responses are triggered when a child or young person is at risk from any cause. Working with the benefit of hindsight, many of the death reviews have shown that the child or young person was showing signs of risk but an appropriate system response was not triggered. The reasons for this include no one recognising the needs, no system in place to seek or initiate action, and the child or young person not being linked to systems that could help. It was also noted that, at times, misconceptions about privacy laws prevented the sharing of information.

5.1.3 Life course transitions

In the first five years of life and after 14 years, the peaks in mortality coincide with periods of rapid transition in the life course (as shown in Figure 5.1). These transitions are linked to developmental stages and, therefore, make all children and adolescents potentially vulnerable. It is important to consider how this pattern may also relate to system problems and the need to improve existing systems or create new systems that precede or coincide with times of vulnerability and peak mortality.

Gaps in care have been noted in many reviews, often having been identified when information is sought on care history and it becomes clear that crucial players in the continuum did not know who the others were and, consequently, were unable to connect and pass on any concerns.

In the first years of life there is high vulnerability due to physiological and developmental immaturity and parents need guidance and support. According to the CYMRC data, 47.4% of post-neonatal deaths in New Zealand are due to SUDI (as shown in Chapter 1 and Appendix C, at http://www.cymrc.health.govt.nz, *Fifth Report to the Minister of Health: Reporting mortality 2002–2008*). Meanwhile, 35.1% of deaths of children aged 1–4 years are due to unintentional injury (as shown in Appendix D, Figure E.2, at http://www.cymrc.health.govt.nz, *Fifth Report to the Minister of Health: Reporting mortality 2002–2008*). Both of these causes of death are considered preventable.

Although the primary cause of death for the infant age group changes after the first year, there are common themes related to system issues. The post-natal care continuum relies on links between the lead maternity care provider covering the ante-natal, birth and follow-up care through to 4-to-6-weeks. At this stage, the responsibility is transferred to a Well Child provider and GP until the child starts school, with the GP remaining the pivotal health contact.

The quality of care in the first year of life is dependent on this three-way care continuum functioning well. Gaps in this system can break the chain of care. The continuum links may not be established or maintained, leading to crucial interventions being missed that can have life-threatening consequences for the most vulnerable infants. The recommendation that DHBs monitor the proportion of infants who have a named GP at age four weeks (Chapter 1) is a potential quality indicator for health care coverage.

After 14 there are increased challenges and risks associated with the developing independence of the young person. As stated in Chapter 3, this stage of life is marked by young people spending more time away from their family and whānau, exposed to more dangers and taking greater risks, which are a natural part of this stage of development. These challenges and risks require greater involvement from parents at a time when parental involvement is often declining fast.

In the health care system there are many age-related transitions that occur at this time of life, and these transitions will determine future pathways for the patient through the health system. Children who have been with paediatric services are frequently transferred to adult services around the age of 15, although it is important to note that there is a variable level of flexibility to allow provision of developmentally appropriate care to fit the needs of the individual young person.[57] In mental health and alcohol and other drug services, the age for transfer to adult services is deliberately set in the Ministry of Health National Service Framework as falling between the 18th and 20th birthdays.[58] The intention of this was to allow opportunity for the developmental needs of the young person to be considered so the best transfer to suit the individual within this two-year period could be planned; however, well-developed mechanisms to make this happen do not exist in every DHB.

Other government agencies shift young people to adult services at varying ages. Child, Youth and Family discharge clients at 17 years of age.[59] For education, the care responsibilities are linked to the legal requirement for children to be enrolled in school up to

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[57] *The New Zealand Health and Disability Sector Standards (Children and Young People) Audit Workbook* (Standards New Zealand 2004) supports the goal of developmentally appropriate care in developmentally appropriate settings.

[58] The Ministry of Health National Services Framework sets the service specifications for Mental Health Services.

[59] However Section 110 guardianship orders continue until the young person is 20 years of age.

the age of 16 years. Those with special needs may continue to have educational support through to 21 years. The Independent Youth Benefit is available in specific circumstances for those between 16 and 18 years of age, but eligibility for most benefits begins at age 18. Justice deems a young person an adult at 17 years.

All of these variations create fragmented care and gaps through which young people can go 'missing' in the system, increasing the chances of not getting the full level of support needed with, in some cases, lethal consequences. An important element of any transition is having someone who supports continuity of care across the transition, so not all services change at the same time. *The Child and Young People Audit Workbook* (Standards New Zealand 2004) has many comments around planning for successful transitions stressing the importance of it being a planned and graduated process.

5.1.4 Identification of at-risk infants, children and young people

The mortality review process highlights how risk factors often cluster together in such a way that death results. Each chapter of this report highlights how this occurs for different conditions. Many recommendations made by the local child and youth mortality review groups make it clear that appropriate tools to identify risk are often not being used. This is a common factor across key agencies, including health services, education, welfare and police. Information gathered from the local child and youth mortality review process shows that some risks appear quite obvious, but reviews still indicate that too often such risks go unidentified or no agency takes the lead in initiating the appropriate action.

More widespread use of risk assessment tools needs to occur and more tools should be developed. Every time a tool is used it must lead naturally to an intervention. The sort of toolkit proposed for SUDI prevention is an example of a system that completes the loop from risk identification to intervention (see Chapter 1).

Towards Wellbeing: A service response to young people in need
by Dr Marie Connolly PhD, Chief Social Worker, Ministry of Social Development

In 2000, Child, Youth and Family introduced a new set of initiatives to strengthen their services to young people at risk of suicide. They released a new set of tools that could be used at any time when a social worker is concerned about a young person's behaviour or presentation. The tools provide practitioners with a guide for recognising and assessing the needs and strengths of young people.

In addition to the tools, the "Towards Well-being" programme was established. Recognising the particular vulnerability of young people engaging with the service and the complexity of the work, the "Towards Well-being" programme was designed specifically to provide expert advice to social workers.

The clinical advisors, who are external to the statutory service, help the social worker pull together the young person's individual plan and assist in monitoring the plan's progress. They also offer advice and assist with the provision of services from external agencies. Social workers have reported a positive working relationship with the clinical advisors and benefit from the assistance as well as having another eye over their cases.

The tools and the "Towards Well-being" programme more generally have been effective in strengthening the professional safety net around young people at risk. An agreement between professionals also enables the clinicians to access information regarding a young person at risk by receiving alerts when the tools have been completed. This allows for a rapid response to the situation and supports the ongoing conversations that strengthen the young person's care.

The tools, the programme and, in particular, the high-level professional support has enhanced Child, Youth and Family practitioners' understanding and responsiveness to young people who are self-harming or at risk of suicide.

5.1.5 Lack of services

There are also deaths that have occurred when it was clear that the child or young person needed care but there were simply no care services available. This type of systems issue can stem from a combination of factors, such as agencies being unable to meet the presenting workload, services not provided in the area, services that are not targeted towards the specific needs of children and adolescents, or admission criteria that unintentionally create gaps.

Nationwide, some services are clearly better developed for adults than they are for older youth. These include mental health services, alcohol and drug programmes, and tobacco cessation programmes. This has been apparent in those reviews where the transition from child to adult services has missed developing risks and opportunities for intervention. Several local reviews highlighted the fact that children living in rural areas face greater challenges in accessing services.

It is vital that all services are planned and delivered with the patient journey (client journey) in mind. This requires a holistic perspective, and seeing things through the eyes of a child or young person. Within the health sector, someone should have an overview of all services for children and young people in a region. It is then possible to plan and purchase the services needed during patient journeys, rather than purchasing groups of services that may not be connected to one another, inevitably leaving gaps. Some DHBs have overcome this problem by appointing child and youth portfolio managers to support the development of a balanced portfolio of services to meet community needs.

Initiatives like Strengthening Families are also a step towards greater collaboration and co-ordination of services that are tailored to meet the needs of individual families.[60]

Some reviews highlighted the needs of the increasing numbers of children and young people in New Zealand who do not have English as a first language. They may be at risk as the health system is challenged in finding ways of providing services in their language that are sensitive to their unique cultural needs. Professionals have a responsibility to recognise when interpreters are needed and to make sure they are available and provided.

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[60] 'Strengthening Families is a cross-sectoral, whole-of-government initiative which uses a structured process of government agencies and community organisations working together to achieve better education, housing, health and social outcomes for families. Both government and non-government/community organisations participate in Strengthening Families.' Source: http://www.strengtheningfamilies.govt.nz, accessed 9 September 2009.

5.1.6 Services should form a chain of care

The local review process has highlighted cases where a lack of engagement with services, particularly the health system, may be a sign of risk that can go unidentified. This can occur following referral between providers, while making the transition from child to adult services, or when transferring from a general to a specialised health care provider. Cases are documented where a child has been discharged from one service but has not had any follow-up to make sure that another service has picked up care, or that discharge instructions are being followed. These breaks in the chain of care also feature in a number of reports from the Health and Disability Commissioner. The Commissioner has drawn our attention to a number of cases that highlight issues with regard to care coordination where poor co-ordination of care has contributed to poor outcomes.[61]

It is important that health services view themselves as components in an unbroken chain of care. Every "discharge" or referral should be regarded as a transfer of care to another, with the last point of contact needing to remain responsible until the next one picks up the care responsibility. In the context of transient involvement this principle remains important (eg, a patient seen for the first and only time). The local child and youth mortality review groups are ideally placed to identify and rectify breaks in the chain of care by taking action and initiating changes to systems using the organisational links of their group membership.

When a child or young person does not show up for an appointment, it should be viewed as a time of concern.[62] Failure to show up for an appointment might indicate signs of neglect in the home (ie, parents not encouraging care) or, in the case of mental health care, it might suggest the child is at high risk for self-harm. The local review process has shown that failure to show up for an appointment is particularly common prior to suicide (see Chapter 4). There are a number of examples that highlight the need to follow up when a person does not attend an appointment.[63] These examples also emphasise the need for follow up after discharge from care and illustrate the need for continued work on the goals outlined in the *New Zealand Suicide Prevention Action Plan 2008–2012* (Ministry of Health 2008a). Some services are now being designed with this principle in mind. The B4 School Check system now tracks referrals from source to agency to which they are referred with follow up to ensure the visit took place.[64]

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[61] Case information can be reviewed on the Commissioners' website at www.hdc.org.nz. Specific case numbers are: 07HDC10316, 08HDC04311, 00HDC02720, 01HDC01802.

[62] In her 2006 Master's thesis, Kaye Hudson found that in the Capital & Coast DHB there was a growing number of patients who did not attend (DNA) their follow-up appointments in the outpatient department. Hudson argues: 'The assumption is often made when talking about DNA rates that the failure to attend outpatient appointments is the fault of the individual patient. As identified by previous studies undertaken both internationally and nationally, hospitals also contribute to non-attendance at outpatient clinics. In this study over 50% of the participants identified either hospital administration failures or hospital barriers as the reason for their non attendance.' *Capital and Coast District Health Board's Contribution Towards Patients' Non-attendance at Outpatient Clinic*s, Department of Public Health, University of Otago, Wellington. URL: http://www.uow.otago.ac.nz/academic/dph/Publicationsreports/ Kaye%20Hudson%20abstract.doc, accessed 9 July 2009.

[63] As this section draws on actual cases, please note that careful attention has been given to make sure that all cases are not identifiable.

[64] Personal communication with Dr Pat Tuohy, Chief Advisor – Child and Youth, Ministry of Health.

The local reviews show that it is not uncommon to hear the story of a young person who was admitted to hospital several months prior to death with depression, poly-substance abuse and thoughts of suicide, then discharged to the care of a GP and community health service provider. The young person did not attend any appointments following discharge and later completed suicide. This raises the question of whether follow-up to ensure the young person received care would have prevented their death. It is also interesting to note that the discharge referrals in these types of cases often show no reference to the high risk of substance abuse despite the fact that the *New Zealand Suicide Prevention Action Plan 2008–2012* advocates for improved mental health and addiction services in Goal 2, Action 2.5.

Many of the adolescent suicides reviewed demonstrate the need for strong systems of communication between GPs, alcohol and drug services, community providers and mental health services. They also remind us that we must reach out to young people after they have been discharged from care and/or when they miss appointments.

5.1.7 Risks of relocation

Another risk highlighted by local review was the dislocation of care that can happen if the child has recently moved. If a child has moved – particularly to another geographic region – records may not be transferred. As a result, new care providers will not know about previous conditions or the child may not yet have had time to develop an adequate support network. In one tragic death, the family had recently moved, fracturing established support networks and the child died of family violence before any new supports were in place. No neighbours knew the child, the school did not know of the risks, social agencies had not caught up with the move, and the child died before health agencies were involved. No one agency was to blame but the 'system' had left a gap and the child was not protected – no one was 'watching over' the child.

A similar story is that of a young person who died by suicide shortly after the family relocated. The local child and youth mortality review group concluded from their investigation of this death that the deceased had not had time to establish a support network within available public services or through a network of peers.

These examples illustrate the additional level of vulnerability a person can face when they have recently relocated. Risks associated with lack of support need to be incorporated into the assessments done by the health sector, social service agencies and schools. It is important that each agency continues to offer care until there is certainty that another has picked up the role. It is too easy for services to "discharge" their duty of care without confidence another has picked it up, especially when they move to a new location.

5.1.8 Chronic illness

These underlying systems issues apply to other types of deaths as well. Children and young people with chronic conditions can pose unique risks as they require "long-term support systems centred on the individual" (Standards New Zealand 2004).

The National Advisory Committee on Health and Disability 2007 report, *Meeting the Needs of People with Chronic Conditions*, stated:

> The organisation and delivery of health services has traditionally developed within a cure-focused model concerned with turning acute episodes into survivable events.

Too often this "cure-focused model" of episodic care is transposed to chronic care with little consideration of the special needs of this group. Families with children with chronic conditions are often stretched to full capacity caring for their child and have no time to organise the services of the many agencies involved in care. Long-term complex care requires a team approach, with access to key workers, case managers and integrated care co-ordinators. Without good team work, care can be compromised, with increased risk of death. Risks arise from compromised clinical care, difficulty making the transition from one service to another, or failure to provide adequate support to families.

An extreme consequence of stress for families of children with chronic conditions is illustrated in the report into the death of Casey Albury (Werry 1998). Casey was a 'moderately to severely intellectually handicapped' young woman with autism who was killed by her mother in 1997. Casey's mother was found guilty of manslaughter, but it was widely understood that part of her distress was caused by 'a sense of injustice' because she felt that she should have been provided with more respite care from the state (Ibid: 5). While cases like this are mercifully rare, this case emphasises the importance of supporting families adequately.

5.1.9 Lack of information sharing

Some local reviews indicated that risks had been identified but information was not shared in a timely manner and/or to the appropriate party in order to prevent the death. This lack of co-ordinated information sharing, both within the health sector and across government agencies, is common. There are many examples of cases where children and young people were known to government agencies but the agencies failed to share vital information with one another. At other times, agencies and health care professionals failed to take action when signs of risk were evident because no one organisation felt it was their role to take the lead in initiating the appropriate life-saving responses.

Lack of information sharing because of privacy concerns contributes to death in two main circumstances. The first is when a child is at risk of abuse or neglect but there are no actions taken to get additional support to the care givers. Although death directly from child abuse is relatively rare, neglect or poor parental supervision is a relatively common contributing factor in deaths.[65] The second circumstance is when clinical care is compromised because important information is not shared between health services and families, or between health services and community providers. This is especially important for the quality of care of young people at risk of suicide and self-harm.

A key step forward would be to reduce the barriers presented by concerns about breaching aspects of the Privacy Act and the rights of children and young people. The Children, Young Persons, and Their Families Act 1989 (the CYPF Act) and the Health Information Privacy Code 1994 (Office of the Privacy Commissioner 2008) contain clear guidelines on reporting concerns where risk of harm is a priority. Section 15 of the CYPF Act states that:

> any person who believes that any child or young person has been, or is likely to be, harmed (whether physically, emotionally, or sexually), ill-treated, abused, neglected, or deprived may report the matter to a social worker or a member of the police.

Furthermore, section 16 of the CYPF Act states that:

> no civil, criminal, or disciplinary proceedings shall lie against any person in respect of the disclosure or supply, or the manner of the disclosure or supply, by that person pursuant to section 15 of information concerning a child or young person (whether or not that information also concerns any other person), unless the information was disclosed or supplied in bad faith.

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[65] Further work is needed to define how often it contributes. The improved analysis planned for the CYMRC database should address this gap.

Similarly, Rule 11 of the Health Information Privacy Code 1994 (Office of the Privacy Commissioner 2008) states that a health agency that holds health information must not disclose the information unless the agency believes, on reasonable grounds, that the disclosure of the information is necessary to prevent or lessen a serious and imminent threat to (i) public health or public safety or (ii) the life or health of the individual concerned or another individual.

It is important to remember that the Privacy Code is written to give *protection* in the event of a legal or other challenge to disclosure of appropriate health information; it is not intended to prevent appropriate disclosure.

Fortunately, there are some very good examples of information sharing at the local level to ensure children and families get the best support. For instance, some DHBs are developing teams to identify families in need of extra support before the birth of an infant. When such a need is identified, a 'wraparound' care team is developed so that the needs of the family are supported before abuse or neglect can become established. Key players in this sort of work involve the health sector, Child, Youth and Family (CYF), the police, mental health services, the Family Violence Intervention Programme, Well Child providers and drug and alcohol services.

5.1.10 Improving care and support after the death of an infant, child or young person

The death of a child or young person is a tragic event that most services do not encounter very often. A number of local groups have identified problems with the processes relating to "after death care." It seems the tragic and infrequent nature of child and youth death has led to systems not being well developed in some services. The CYMRC has therefore suggested that LCYMRGs perform work related to the development and refinement of a local care pathway. The issues that need to be addressed in guiding good practice may include:

1. using first responders (police, ambulance, or primary care) to trigger a chain of supportive care

2. supporting the family in understanding after death processes, the Coroner's role, and post mortems

3. an organised system that provides support for families, including those where death occurs without health system involvement and considers the needs of siblings and/or children of the deceased

4. access to appropriate post mortem examinations

5. access to palliative care

6. ensuring that key stakeholders are informed of the death (eg, general practitioners or the Ministry of Education Traumatic Incident team)

7. directing the family to services and information

8. healing care for the wider community

9. "switching off" care systems and automated recall systems within health and other services[66] – all files, recall systems and registers being deactivated so that all those involved in care know the child has died.

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[66] Complex systems support children and young people in the community. It is important these systems "switch off" or modify their actions after the death of a child. Too often LCYMRGs have noted distress has occurred because of home visits by workers unaware of deaths, phone messages, or letters recalling children for care. With the development of many databases, information about children is stored in many places, often in a very fragmented way. It can therefore be challenging to ensure all these systems are notified of death in a timely manner.

Post mortem examinations can be a very important part of the after death pathway. For this reasons, the CYMRC was represented at the workshop on Perinatal Pathology organised by the PMMRC (see appendix A11 at http://www.cymrc.health.govt.nz). In addition to concerns about the sustainability of Perinatal Pathology Services, the CYMRC notes difficulties in accessing appropriate post mortem assessment in some parts of the country and concerns about the workforce provision. The development of a clinical network for perinatal and paediatric pathology is seen, therefore, as a high priority.

5.2 The CYMRC leading change at the local level

The systems issues outlined above that have been highlighted by local child and youth mortality review groups require both local and national action. Although many of the review groups are still in their establishment phase, the review process is already demonstrating that the CYMRC model of mortality review is a powerful tool for local change because it promotes inter-agency and cross-sector co-operation and collaboration. It is very easy to overlook the extent to which the LCYMRG develops a collegial environment that supports good practice and provides direct feedback on strengths, thereby reinforcing successful work.

Outside of the health sector, local changes have occurred within local government, the police, the Fire Service and in children's organisations as a direct result of mortality review. In addition, a range of local-level health sector changes are also evident in mental health services, midwifery practice and in the closer alignment of SUDI services. The following improvements have occurred as a direct result of the local child and youth mortality review process.

- A simple system improvement was implemented in one DHB area following the death of an infant who required urgent transfer to another care centre. Communication with the other centre had been delayed at least an hour by the electronic switchboard and answering system. Because this was not the first time such a delay had occurred, a list of the direct telephone numbers of clinicians at the other centre has now been distributed and laminated versions have been placed in appropriate locations throughout the DHB.

- Following mortality review of the death of a child in a fire, the development and implementation of Fire Service training programmes with local organisations that work with children was facilitated in order to reduce the risk of future death from fire.

- In one DHB it was recognised that lack of access to translation services for care of new migrant families was a concern in a case. The issue was flagged as a DHB risk and access was improved.

- Following a case where failure to attend an appointment was followed by a completed suicide, a DHB developed a "did not attend policy" within mental health services and the wider use in other services is being considered.

- In a DHB region inconsistencies in the collection and reporting of information following the review of sudden unexpected deaths in infancy (SUDI) were noted. The police representative on the local review group initiated improvements to their system at a local level that have since been taken up as a national initiative.

- In one region changes have been made to midwifery practice as a result of a midwife's participation in mortality review. Information gathered in the review process led to changes in working with mothers in the methadone programme. The midwife had, as a result of reviews, made a strong commitment to provide more information on safe sleep environments and to advocate for SUDI prevention and risk reduction, particularly bed sharing. Modelling of this approach by the midwife and promotion to other midwives has resulted in more of the local midwives adapting their approach to better incorporate these issues.

5.2.1 The need for national action

The CYMRC is working to develop a system for sharing innovations identified and championed by local child and youth mortality review groups across their national network and with other organisations that participate in the review process. The local review groups are clearly a powerful tool for local change, but some issues require national collaborative effort as well. These national-level actions may require ministerial support across a number of sectors to get traction and change.

5.3 Recommendations by the CYMRC on systems improvement

National recommendations, prompted by local review findings, have identified key points of system change that need to be addressed if there is to be a long-term reduction in preventable deaths of children and young people.

5.3.1 Policy

1. The Government needs to continue to promote intersectoral communication, planning and review. This needs to be in each department's outputs, and funded.

2. The current restructuring of the health system provides an opportunity to better support a holistic approach to Child and Youth, to increase collaboration and co-ordination and reduce service gaps by providing oversight from a single section or division within the Ministry of Health or National Health Board.

3. Co-ordination is needed between sectors to develop effective responses that address the types of deaths that cross boundaries between government agencies. Driveway deaths, farm transport deaths and recreational off road are examples where leadership and co-operation are required to reduce the number of deaths and injuries.

5.3.2 District Health Boards

4. The health sector has a duty to use appropriate risk assessment tools and where risk is identified interventions should occur.

5. All DHBs need a team approach and leadership to create and support a holistic approach to child and youth health. The CYMRC recommends a portfolio manager for children and youth or similar in every DHB.

6. All DHBs should have a system to plan and implement transition of young people from paediatric to adult services.

7. Additional services should be developed that recognise and meet the needs of young people (defined as those aged 12–24 years), and improve access for those living in rural areas.

8.   All DHBs should develop a pathway outlining local care after the death of a child or young person, including planning for access to appropriate post mortem examinations where indicated.

9.   All DHBs should ensure systems provide access to sustainable paediatric pathology services in every district.

5.3.3 Practice points

10. Professionals must recognise that the transition between care providers can be a vulnerable time for children and adolescents.

11. Professionals should consider how systems ensure continuous care after referral or discharge and for those that do not attend appointments.

12. Professionals should engage in ongoing training across all the sectors working with children and young people, particularly health, to ensure the legislated pathways for sharing information about risk are understood and managed collaboratively.

13. Professionals have a responsibility to recognise when interpreters are needed and to make sure they are available and provided.

> "When we link data from different sources after death, we frequently recognise where the system of care could be improved before death. We all need to keep thinking about how we can link data better to support care of the living."
>
> Nick Baker – Chair CYMRC.

Abbreviations and Glossary

ACC	Accident Compensation Corporation. ACC administers New Zealand's accident compensation scheme, which provides personal injury cover for all New Zealand citizens, residents and temporary visitors to New Zealand. In return, people do not have the right to sue for personal injury, other than for exemplary damages.
Bed sharing	The use of a common surface on which to lie down, but not necessarily sleep. The term 'co-sleeping' refers to sleeping together on the same surface, and implies specifically the adult sleeping with an infant on the same surface.
Case conferencing	A formal, planned and structured event with the goals of providing holistic, co-ordinated and integrated service review across providers, and reducing duplication. Case conferences are usually interdisciplinary and include one or more internal and external providers. Case conferencing differs from local mortality review group meetings because it includes all those who were involved in the care of the child or youth, whereas a local mortality review group (in order to comply with the Act) has agents representing the various organisations – not necessarily those directly involved. Those directly involved with the child or youth may attend the local mortality review group, but only individually.
Chief Medical Officer (CMO)	A senior doctor who is part of the executive team of an organisation and who provides leadership on a number of matters, such as clinical quality improvement, risk management and health-related legal issues.
Child, Youth and Family (CYF)	A service of the Ministry of Social Development and part of a network of agencies aiming to build an environment in which child abuse is not tolerated.
Cross Departmental Research Pool (CDRP)	The Cross Departmental Research Pool supports policy-related research in government departments. Departments are able to bid for funding (transferred from Vote: Research, Science and Technology to their Vote) to carry out research of critical cross-portfolio interest. The CDRP money is managed jointly by the Ministry of Science and Technology and the Foundation for Research, Science and Technology (see http://www.morst.govt.nz).
District Health Board (DHB)	DHBs are responsible for providing, or funding the provision of, health and disability services in their districts. There are 21 DHBs in New Zealand and they have existed since 1 January 2001, when the New Zealand Public Health and Disability Act 2000 came into force.
Estimated resident	The denominator for mortality rates is taken from the estimated resident population (for 30 June in the year of death), as published by Statistics New Zealand. This is based on a projection of the count, including: all residents in the most recent Census, and residents who were temporarily overseas at the time of the most recent Census, with an adjustment up for residents who may have been missed by the Census and an adjustment down for anyone who may have been counted twice. Visitors from overseas are excluded (see http://www2.stats.govt.nz).
High-risk or reckless behaviour	Deliberate behaviour (eg, butane inhalation or binge drinking) that would usually be avoided because of the possibility of severe injury or death, but where there appears to be no intent to self-harm.
Information Directorate	Formerly known as the New Zealand Health Information Service (NZHIS). A business unit of the Ministry of Health responsible for collecting data and reporting health-related statistics.
Lead Maternity Carer (LMC)	A health professional who is responsible for providing or organising maternity care through pregnancy, birth and the postnatal period. LMCs may be midwives, general practitioners or obstetricians.

Local Child and Youth Mortality Review Group (LCYMRG)	These are local groups of agents of the Child and Youth Mortality Review Committee based in DHB regions. They work locally and report to the CYMRC, and also to the governance section of the DHB.
Mortality Review Data Group	Otago University staff who are contracted by the Ministry of Health (on behalf of the CYMRC) to manage a national mortality review database in accordance with a formal contract between the Ministry of Health and the University of Otago.
National Health Index (NHI)	The NHI is used to help with the planning, co-ordination and provision of health and disability support services across New Zealand. The National Health Index stores NHI numbers and demographic details. The number is a unique identifier that is assigned to every person who uses health and disability support services in New Zealand.
New Zealand Health Information Service (NZHIS)	Today known as the Information Directorate. A business unit of the Ministry of Health responsible for collecting data and reporting health-related statistics.
Occupational Safety and Health (OSH)	Part of the role of the Department of Labour is to provide best practice information and guidance to assist New Zealand businesses with health and safety in the workplace.
Organisation for Economic Co-operation and Development (OECD)	The OECD brings together the governments of 30 countries committed to democracy and the world market economy (see http://www.oecd.org).
Quaternary	The level of health care above tertiary care. It usually refers to highly specialised services delivered by specialist clinicians in large teaching hospitals.
Risk competence	The capacity of individuals to recognise risk and dangers, to handle and cope with them, to make responsible decisions to avoid harm and the ability to learn about and integrate challenges.
Risk-taking	Active, voluntary behaviours associated with heightened risk of injury or death such as reckless use of alcohol, motor vehicles or natural hazards. Different types of risk-taking behaviours tend to cluster.
Safekids	The injury prevention service of Starship Children's Health and a member of Safekids Worldwide (see http://www.safekids.org.nz).
SIDS	Sudden infant death syndrome. 'The sudden death of an infant under one year of age which remains unexplained after a thorough case investigation, including performance of a complete autopsy, examination of the death scene, and review of the clinical history' (Willinger et al 1991).
Strengthening Families	A service that provides co-ordinated support for families who are working with more than two organisations. The organisations and the family work together to develop joint solutions, rather than each organisation dealing with one part of the problem and never seeing the bigger picture (see http://www.strengtheningfamilies.govt.nz).

Sudden unexpected death in infancy (SUDI)	This is a broader definition than SIDS, in that SUDI includes both explained and unexplained causes of sudden unexpected death. The more common causes of explained SUDI include unrecognised illness or infection, heart rhythm disorders and metabolic disease. In this report these explained SUDI cases have been entered into the sections related to their specific causes.
	Unexplained SUDI deaths in infancy is the term currently used by CYMRC which encompasses SIDS as well as infants found in adult beds where no direct evidence of overlying exists, and other similar deaths where a thorough post-mortem examination and death scene investigation do not give an obvious cause of death. In the New Zealand context this also includes babies where the investigations normally required are not actually achieved by the investigating agencies. These deaths in some areas are called "unascertained" but in this report are included in the unexplained SUDI group.
Undetermined intent	In this report this has been given as the cause of death where the person was participating in what the CYMRC has determined as 'high-risk behaviour' (see above). Although the death was accidental, there are important preventable factors associated with such deaths (eg, binge drinking). CYMRC data is likely to contain a higher percentage of 'undetermined intent' deaths when compared with the Information Directorate data, because CYMRC's focus is on prevention. For more information on determining the cause of death, see Appendix B.
Well Child services	The publicly funded health service in New Zealand with the primary objective of supporting families/caregivers to maximise their child's developmental potential and health status between the ages of 0 and 5 years.

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